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ABSTRACT

This research project sought to identify, at a local community level, the needs and concerns of American Indians with disabilities. The selected target community was Denver, Colorado, and its surrounding metropolitan area. Data were collected through 100 face-to-face interviews with a volunteer population of American Indians with disabilities. The interviews covered general information, disability information, services information (formal support systems), consumer concerns, educational information, social information (informal support systems), and employment information. A wide range of disabling conditions was reported, including arthritis, diabetes, substance abuse, visual impairment, heart problems, orthopedic disorders, and emotional disorders. Only 25% of the survey population was employed. Access to transportation, affordable housing, and medical care were viewed as problems. Lack of outreach from social service agencies was of primary concern. Less than half of those surveyed felt matisfied that social agencies treated them with respect and dignity, and only a 'hird were satisfied with advocacy efforts in the community. This final report of the research project describes the people involved in the study, development of the survey instrument using the Concerns Report Method, implementation of the survey, results, conclusions, and recommendations. Appendices, which comprise over half of the report, contain administrative correspondence, a training agenda, job description of the on-site coordinator, interviewer project evaluation, information on outreach to minorities with developmental disabilities, and other administrative materials. (Includes 27 references.) (JDD)



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The Assessment of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change

Final Report

1990

Revised January 1991

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SUMMARY

This research project represents a continuation of the efforts of the American Indian Rehabilitation Research and Training Center (AIRRTC) to identify the concerns of American Indians with disabilities at a local community level. Through earlier research conducted by the AIRRTC, it has been demonstrated that significant differences occur nationwide in the prevalence of disability, and the employment status of American Indians who have disabilities. The identification of problems and their solutions by State VR Directors and other rehabilitation service providers also vary across regions, tribes, and between rural and urban American Indians. It has become clear that efforts to improve the rehabilitation of American Indians must include community-level needs assessments; local agency planning and changes in policy can only benefit by the results of these assessments specific to a given community.

Based on a community needs assessment which consisted of telephone interviews with administrators from Indian Urban Centers, Denver and the surrounding metro-area, was selected as the target community in which this project would be developed. The AIRRTC conducted this research in consultation with the Research and Training Center on Independent Living at the University of Kansas, as one focus of the study was to determine the appropriateness of the Concerns Report Method when used with an American Indian population. Supporting agencies of the research included Colorado Rehabilitation Services, Denver Indian Center, Denver Indian Health and Family Services.

At an advisory meeting of service provides and consumers held on August 29, 1989 at the Denver Indian Center, it was strongly recommended that members of a working group, charged with developing the survey instrument, be identified both by service providers and by American Indian elders who knew persons with disabilities. It was also strongly recommended that the elders be invited to attend a dinner meeting where the project would be explained to them. The elders were asked to bring a potential candidate for the working group to the meeting. On September 16, 1989 approximately 36 persons



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attended the first consumer-oriented planning meeting for this project held at the Denver Indian Center. At this and a subsequent meeting, consumers identified issues to be included on the survey instrument. Both the Denver Indian Center and the Denver Indian Health and Family Services offered their facilities for meetings of this project on an asneeded basis. Sister Marie-Therese Archambault (Sioux) was hired as the on-site coordinator for the project.

A public meeting where the results of the study were presented was held on April 17, 1990 at the Denver Indian Center. Persons interviewed, as well as any other American Indians with disabilities in the Denver-metro area, were encouraged to attend to provide recommendations for community services which would better meet their needs. The results of the study were based on data collected through 100 face-to-face interviews. On average, the Indian people surveyed had lived in the Denver area for 18 years, reported 2.8 disabling conditions each, and were 46.5 years of age. Sixty-seven percent of the sample were Sioux; 55% were female. A wide range of disabling conditions were reported, including arthritis (37%), diabetes (33%), substance abuse (24%), visual impairment (21%), heart problems (16%), orthopedic disorders (14%), and emotional disorders (12%). In terms of functional limitations, 64% reported having problems with walking, 62% with lifting, and 50% with working on a job. A primary concern identified by the survey population was the lack of outreach services provided by social agencies.

Recommendations for services which would address the concerns of American Indians with disabilities in Denver, Colorado included the need for: in-home outreach; client advocates who could provide case-management services, e.g. secure transportation; specialized vocational rehabilitation services to be made available to the Indian community, and increased employment opportunities. It was also recommended that American Indians with disabilities need to recognize themselves as a community; service agencies need to provide information regarding the legal rights of persons with disabilities, as well as information regarding the "health and wellness" aspects of disability. Finally, service



agencies in Denver must renew their efforts to train, hire, and retain American Indians to serve people with disabilities.



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"The predominant pattern in American society has been for Indian people to be either degraded, totally ignored, or celebrated as a romantic symbol of a past era. . . .

From a practical perspective, this disregard for living people, as opposed to the fascination with ancient ruins, may be evidence of very misplaced attention. . . .

The social and economic conditions of urban Indian communities indicate that something is lacking in urban planning and public policy."

Bryan Higgins Geographer 1982



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Many people, including individuals representing organizations, contributed to making this research project a success. After a year's work, it is not possible to say who contributed "the most;" the research was truly a community effort. Therefore, the following list of individuals, and their organizational affiliation, is not presented in order of contribution, or amount of time spent on the project. It is simply a list of individuals and organizations, in alphabetical order, whose encouragement was felt, and appreciated, in carrying out this study.

Colorado Rehabilitation Services

Denver, Colorado James Weiland, Coordinator for Native American Programs

Denver Indian Center

Denver, Colorado
Wallace Coffey, Executive Director
John Compton, Assistant Executive Director
Margaret Tyon, Senior Citizens Outreach Coordinator

Denver Indian Health and Family Services

Denver, Colorado
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Research and Training Center on Independent Living
The University of Kansas
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Barbara Bradford, Associate Trainer



The Assessment of a Model for Determining

Community-Based Needs of American Indians with Disabilities through

Consumer Involvement in Community Planning and Change

In referring to community-based research, Kelly, Munoz, and Snowden (1982, p. 343) have stated that "research is not just a scientific task," and insist that the people affected by research must be given "careful consideration." They suggest that community-based "research be done by persons who have the commitment and capacity to seek out cordial, reciprocal relationships" (p. 348); these authors speak of community "ownership," "collaboration and mutual learning," "trust," and researchers being "open" to suggestions from the community. This view of the importance of involving the subjects of research throughout the process of research is consistent with the philosophy of Northern Arizona University's American Indian Rehabilitation Research and Training Center (AIRRTC), and formed the parameters by which the research described in this report was accomplished.

According to the AIRRTC's mission statement, "Individuals who are the recipients or users of the Center's research and training efforts are included in the design, conduct, implementation, interpretation, and dissemination of Center activities" (Johnson, 1988, p. 5). The commitment to include input from individuals affected by research, into the design of research, is also derived from a primary goal of the AIRRTC, that is, to assist American Indians in their efforts at self-determination. In an address entitled "Self-Determination at the Community Level," Bowe (1989) suggested that to ensure consumer involvemen., the following would need to occur: "First, help people with disabilities to openly and unabashedly acknowledge their needs; second, teach people with disabilities how to influence the decision-making process in public and private organizations; and third, guide people with disabilities in identifying allies with whom they can make common cause."

Bowe's recommendations aptly summarize the research efforts of the AIRRTC in assisting American Indians who have disabilities to identify their community-based needs.



As a basis for understanding the needs of American Indians who have disabilities and who live in urban areas, it is important to understand the history regarding the migration of Indian people to urban areas. Space limitations do not allow for a comprehensive review of the literature; therefore, only a brief review of issues related to urban American Indians in general is below, followed by a summary of issues related to American Indians with disabilities.

The Urban American Indian

During the 1950's and early 1960's, federal funds were used in an effort to assimilate Indian people into the majority society; a major component of this effort involved relocating American Indians to cities for jobs or job training (See, e.g., Fixico, 1986; Higgins, 1982). After being accepted for relocation, and arriving in the city, "the newcomer received a check to be spent under the supervision of the relocation officer. Next, the officer usually accompanied the new urbanite to a nearby store to purchase toiletries, cookware, groceries, bedding, clothes, and an alarm clock to insure punctual arrival at work" (Fixico, 1986, p. 136). However, many failed to adjust to urban life, perhaps, in part, because they "were often resettled by the BIA in areas where they had little contact with other Indians" (Johnson, Joe, Locust, Miller, & Frank, 1987, p. 9). In addition, the work which American Indians were able to obtain was not always permanent. For example, according to Fixico (1986), "Throughout the reservations, BIA workers circulated brochures and pamphlets suggesting that a better life awaited Indians in urban areas. Pictures of executives dressed in white shirts, wearing ties, and sitting behind business desks insinuated that similar occupational positions could be obtained by Indians" (p. 139). The reality for many was placement "in seasonal railroad and agricultural work, the lowest paying and least secure type of employment" (Fixico, 1986, p. 138). While "federal Indian policy remained rigorously aimed at quickly assimilating Indians into American society," Urban Indian centers were developed to assist Indian people in filling the void created by leaving the reservations (Fixico, 1986). These centers provided



emergency housing, food, clothing, and counseling, as well as opportunities for socialization. As a result, "mutual tribal concerns and interaction dissolved many barriers between tribal groups who had never before associated with each other" (Fixico, 1986, p. 156).

According to Fixico (1986), "relocation climaxed between 1952 and 1957, when over 17,000 persons received services" (p. 148); in 1956 alone, "BIA workers processed 5,316 relocatees through four offices--Chicago, Denver, Los Angeles and San Francisco" (p. 142). Not surprisingly, "the end result of relocation is that over one-half of today's Indian population now resides in urban areas" (Fixico, 1986, p. 183). However, as Metcalf (1982) has pointed out, many Indian people have come to the cities simply to join relatives and friends who may have been part of the relocation program; she concluded that "the Bureau program is, therefore, indirectly responsible for bringing a sizable number of unofficial relocatees into the city" (p. 73). Unfortunatel; ", "in many cases, urban Indians have traded rural poverty on reservations for urban slums" (Fixico, 1986, p. 156). According to Metcalf (1982), "25 years of Relocation . . . has succeeded in increasing substantially the probability that young Indian families will live at least part of their lives in urban poverty and that Indian women will be raising their children in city slums" (pp. 74-75). For example, in reporting on the situation of the approximately 20,000 American Indians living in Chicago, Martin (1980) has concluded that "being Indian in the big city can itself be lethal" (Section 2, p. 1). He found that:

Indian babies have a 50 per cent better chance of dying at birth than white babies. They will grow up in homes that are three times more likely to be substandard than those of other city dwellers. Nearly three of four will drop out before finishing high school And, finally, the ravages of alcoholism, infectious disease, and poverty will all too often coalesce in early death (Section 2, p. 1).



American Indians and Disability

In summarizing the results of AIRRTC research conducted to determine the special problems and needs of American Indians with handicaps, O'Connell (1987) reported that the rate at which the State-Federal rehabilitation system provided rehabilitation services to American Indians who are disabled was substantially lower than that for the U. S. population as a whole. Specifically, Rehabilitation Services Administration (RSA) data "showed that American Indians who are disabled appeared to be underrepresented in the State-Federal system . . . in the area of sensory disorders (conditions of the eye and ear), orthopedic impairments due to accidents, asthma and allergies, diabetes, speech conditions, and skin conditions" (O'Connell, 1987, p. 8). Further, when investigating the use of state agency rehabilitative services by adult Native Americans, Morgan and O'Connell (1987) found that "client output after successful rehabilitation closures for Native Americans did not differ from that of the general population. However, the rate of successful closure among Native American clients was substantially below that of the general population" (p. 143).

In terms of difficulties in accessing services, it may well be that many Indian people with disabilities, even in urban areas, are simply unaware of the service agencies which exist, or that, their experience with "economic dependency, psychological depression, and poverty result[s] in passive resistance at best and helplessness at worst" (Johnson, Joe, Locust, Miller, & Frank, 1987, p. 12). In a study which surveyed 38 State Vocational Rehabilitation Agency administrators, White (1987) found that "cultural differences were cited as barriers unless the agencies make a concerted effort to understand the cultural differences and 'contexualize' their outreach and education efforts . . . " (p. 155). White (1987) also stated that:

Half of the respondents reported that many American Indians do not relate to 'the VR system,' adding that relationships to the IHS and BIA are often characterized by dependency, while VR requires self-initiative and commitment to long-term goals.



The historical dependence on federal programs by Indian people was mentioned as a disincentive to participate in vocational rehabilitation (p. 155).

In particular, regarding urban American Indians with disabilities, White (1987) found that the state agency administrators did not perceive language differences to be a barrier to service delivery as "English is spoken by most urban Indians" (p. 156). However, respondents did note the "frequent occurrence of program dropouts among urban Indian clients," and suggested as potential problem areas the fact that "urban Indians often do not have family or cultural support systems and have no identified central agency with whom to communicate," as well as the fact that living in an urban area results in great financial need, which can, ironically, inhibit an individual's ability to participate in a long-term vocational rehabilitation program.

Concerns Report Method. The importance of determining the needs of American Indians with disabilities at the local, individual community level is clear. Problems related to accessing services, and in particular, vocational rehabilitation services, have been identified and summarized at a national level; however, local communities need more specific data in order to open service delivery systems to this population. A methodology for identifying the community service needs of people with disabilities, or consumers, has been developed at The Research and Training Center on Independent Living, The Institute for Public Policy and Business Research, The University of Kansas. Termed the "Concerns Report Method," this systematic approach to identifying needs has evolved from a philosophy which stresses "the importance of input from consumers in setting improvement agendas that are sensitive to the unique aspects of local service contexts" (Fawcett, Seekins, Whang, Muiu, & Suarez de Balcazar, 1982, p. 36).

The <u>Concerns Report Method</u> requires that consumers be involved in selecting issues to be researched, results in data that identifies both the strengths and the problems of a community's service delivery system, and involves consumers in a public meeting to both review the results of the research and to make recommendations for change. Issue



statements which have been identified by a "working group" of consumers are then incorporated into an instrument and distributed to the survey population. Consumers responding to the survey rate each of the issues both in terms of its importance to the individual, and in terms of the individual's satisfaction with the particular service or program. According to Suarez de Balcazar, Bradford, and Fawcett (1989), "to date, 17,039 people with disabilities have completed one of 21 different surveys using the Disabled Citizens Concerns Report Method. Participants came from 487 communities in 12 different states. Sponsoring organizations included independent living centers (ILCs), state vocational rehabilitation agencies (VR), and consumer advisory committees. Local surveys were developed in California, Kansas, Michigan, Minnesota, Missouri, and Montana. Statewide applications occurred in Indiana, Iowa, Kansas, North Dakota, Oklahoma, South Dakota, and Wyoming" (pg. 2).

The <u>Concerns Report Method</u> would appear to be a very useful process to employ in identifying the local service delivery needs of American Indians who have disabilities. Indeed, this method is similar to the approach used by the AIRRTC in each research study conducted. However, it is important to note that the <u>Concerns Report Method</u> has been used primarily to identify the needs of non-Indian consumers. For example, while test-retest reliability measures which have been reported are excellent, that is, "approximately 90 percent of the importance ratings and 80 percent of the satisfaction ratings [varied] by 1 rating point or less" (Fawcett, et al., 1988, p. 18), these data can not be generalized to an American Indian population without further study.

Method

The purpose of this study was to determine the needs of American Indians with disabilities at the community level, with an emphasis on utilizing consumer involvement.

One focus of the study was to determine the appropriateness of the Concerns Report

Method when used with an American Indian population. The Concerns Report Method was chosen because it parallels the AIRRTC standard method of operation in the conduct of



research and training. The design of the study called for the research to be conducted in two phases. Phase I, which has been completed, involved the establishment of the survey procedure as a reliable and valid process for the target population. Phase II will consist of a follow-up study to document whether or not positive community change has occurred as a result of Phase I. Research questions guiding the process are:

- 1. Can the <u>Concerns Report Method</u> be applied in a reliable, valid manner to address the needs of American Indians who are disabled?
- 2. Does the information generated by the <u>Concerns Report Method</u> result in improved rehabilitation service delivery to American Indians with disabilities in the target community?

The research methodology carried out in Phase I is presented below, beginning with a brief overview of the people involved in the study, followed by a description of how the survey instrument was developed, and concluding with a discussion of how the survey was conducted.

Subjects

Based upon a survey which consisted of telephone interviews with administrators from 12 urban Indian Centers, Denver, Colorado, along with its surrounding metro-area, was selected as the target community in which this project would be developed and subjects identified. Colorado ranks 19th nationally in terms of its American Indian population, with 75% of American Indian males and 78% of females living in urban areas (O'Connell, 1987). According to O'Connell (1987), "the percentages of work disabled American Indians in Colorado were 11.3% for males and 11.6% for females compared to 7.8% of males and 6.7% of females who were work disabled in the total population" (p. 117).

Specifically, in terms of the size of the Denver-metro area American Indian population, estimates vary. The 1980 Census identified Denver as an "urbanized area," that is, "a central city or cities, and surrounding closely settled territory" (Bureau of the Census, 1983, p. A-2); the urbanized area of Denver (See Appendix A) was reported as



having an American Indian population of 9,535. Of these individuals, 6,438 reported being over age 16, with 1,153 (18%) reporting a disability. According to Diane Mourning, Associate Planner for Denver's Mile High United Way, the 1989 figures for American Indians in the Denver metro-area were 10,450 (Personal communication, August 18, 1989). There exists, however, a general consensus among Indian leaders and service providers in the Denver community that these data underrepresent the number of Indian people living in the Denver-metro area. For example, John Compton, Assistant Executive Director of the Denver Indian Center, has stated that there are approximately 20,000 Indian people in Colorado, with the majority living in the metro-Denver area. In a presentation at a workshop held November 9, 1989 at the Denver Indian Center entitled, "Culture Alert: How to Make Services Accessible to American Indian Elders," Compton referred to Denver's Indian community as a "multi-nation population," located primarily in Denver County, and with "probably" more Sioux representation than any other among the approximately 50 tribes. He further stated that it was "unusual that there is no one concentration of American Indians in one area of Denver," and concluded that as federal funding has dropped, more Indian people are leaving reservations and coming to urban areas t look for employment.

During August 1989, meetings were held with key administrators and staff of potential sponsoring agencies in Denver. Persons expressing support and interest in participating with this project included:

Denver Indian Center. Inc.
Wallace Coffey, Executive Director
John Compton, Assistant Executive Director
Margaret Tyon, Senior Citizens Outreach Coordinator

Denver Indian Health and Family Services
Rockling Todea, Executive Director
Vera Mitchell, Director, Community Health Services

<u>Colorado Rehabilitation Services</u>
James Weiland, Coordinator for Native American Programs



In addition, meetings were held during August 1989 and September 1989 to secure input into the planning and conduct of this project from key persons including:

Region VIII. Rehabilitation Services Administration Art Zamora, Regional Program and Training Specialist

The Research and Training Center on Independent Living
The University of Kansas
Barbara Bradford, Associate Trainer

Indian Education Program/Denver Public Schools Debbie Echo-Hawk, Coordinator

Denver Center for Independent Living Consumer (Identification withheld)

Denver Indian Center. Inc.
Consumer (Identification withheld)

Sponsoring agencies were asked to assist the AIRRTC in identifying subjects for the survey (hereafter referred to as interviewees). Four primary criteria were established.

Interviewees were to:

- 1) be an American Indian with a physical, intellectual, or emotional disability,
- 2) be between the ages of 14 and 70 (to include both transition age adolescents as well as the older worker)
- 3) not have alcoholism as his or her sole disability, and
- 4) live in the Denver metro area (See Appendix A).

Persons were identified as being an American Indian, and as having a disability, based solely on their self-report. A total of 109 individuals were interviewed; however, of these, five persons were below the age of 14 and three were older than 70. The interviews with these eight individuals are not included in the results presented below. In addition, in one case, a signed "Informed Consent Form for use of the Interview Information for Research Purposes" was not obtained from the interviewee; the interview with this individual was also excluded from analysis. Therefore, the survey population used for analysis in this study includes 100 individuals.



Instrumentation

As stated above, a primary focus of this-research was to assess the effectiveness of the Concerns Report Method in determining the needs of American Indians with disabilities. A critical piece of this methodology involves the "working group" and its role in developing the instrumentation of the survey. According to Fawcett, et al. (1988):

These consumers develop a Concerns Survey, which forms the basis for the method. This they do by reviewing a comprehensive index or menu of several hundred items that covers 18 topic areas, including employment, health, transportation, and housing. The working group selects approximately 30 items of local concern to appear on the survey. . . . Each survey item has two parts: How important is this issue? How satisfied are you with it?" (p. 17).

This approach was modified in developing the survey instrument for this project. At an advisory meeting of service providers and consumers held on August 29, 1989, at the Denver Indian Center, it was strongly recommended that members of the "working group" be identified both by service providers and by American Indian elders who knew persons with disabilities. It was also strongly recommended that the elders be invited to attend a meeting where the project would be explained to them and where dinner would be served in line with American Indian custom. The elders were asked to bring a potential candidate for the working group to the dinner.

On September 16, 1989, approximately 36 persons, including many elders, attended the first "working group" meeting (See Appendix B). The meeting was held at the Denver Indian Center, with a buffet dinner provided through a collaborative effort involving the AIRRTC, the Denver Indian Health and Family Services, and the Denver Indian Center's senior citizen's group. Of those attending, 12 persons identified themselves, or a family member, as having a disability. The meeting was conducted by Dr. Marilyn Johnson, Director, AIRRTC, and Dr. Catherine Marshall, Research Associate, AIRRTC. In



addition, Barbara Bradford, Associate Trainer, The Research and Training Center on Independent Living, the University of Kansas participated in the meeting (See Appendix B). Issues identified as "concerns" included: (a) the need for respite care, (b) the need for accessible housing, (c) the need for accessible transportation, and (d) the need for American Indians with disabilities to have access to information regarding services.

Consumers attending this first working group meeting agreed that a second meeting would be necessary to complete the process of identifying issues to be included on the survey instrument. The second meeting was held on October 17, 1989, again over dinner, at the Denver Indian Center; consumers had been mailed a copy of a draft of the survey instrument prior to the meeting, and were asked to both add and delete items as they saw fit (See Appendix C). Based on issues identified as concerns by consumers at the first meeting, "Issue Statements" were selected by the Principal Investigator, when possible, from the "List of issue Statements for Working Group Members to Design a Consumer Concerns Report Survey," and presented in the format outlined by the Concerns Report Method (Fawcett et al., 1987). Where "Issue Strtements" did not exist to cover the concerns of the "working group," they were developed by the Principal Investigator. As stated above, each "Issue Statement" is rated both in terms of its importance to the individual, and in terms of the individual's satisfaction with the particular service or program. The "Importance" rating ranged on a five-point scale from "of no concern to me" to "very important." The "Satisfaction" rating also utilized a five-point scale, and ranged from "very dissatisfied" to "very satisfied." For those interviewees not familiar with a particular service or program, the statement "I do not know if this service is available" was added to the "Satisfaction" rating scale.

The consumers in attendance at the second "working group" meeting focused on reviewing the appropriateness of the issue statements, both in terms of the content and the format of the items. Several suggestions were made regarding the wording of the issue statements; redundant items were deleted. Several new items were created by combining



issue statements. Suggestions were made to include items related to spirituality and education on the survey instrument. Concern was expressed regarding the "satisfaction" rating, but only in the sense of "I know of two agencies; one I am very satisfied with and the other I am very unsatisfied with. How do I rate my level of satisfaction?" Service providers in attendance were asked to review the demographics on the questionnaire for clarity of wording and importance. They were invited to add any items which might be of particular interest to their respective agencies. Demographic items were derived in large part from a study previously conducted by the AIRRTC involving the Pueblo Indians in New Mexico (Martin & O'Connell, 1986). The instrument also contained demographic questions, as well as items addressing satisfaction with service delivery, which were derived from a questionnaire developed by the Colorado Division of Mental Health (Demmler, Shern, Coen, & Wilson, 1988).

Several recommendations were made by the service providers regarding demographic information and service delivery items; for example, it was suggested that we ask for the birthdate instead of age, that space be left for several tribal affiliations instead of assuming that persons belonged to only one tribe, that we ask about socioeconomic status, and that we ask about how disability affected the interviewee's sexuality. It was explained by at least one service provider that this latter question would be very controversial, and that it could be offensive to elderly persons; however, the group agreed it was important to include.

At the conclusion of the meeting, persons in attendance were invited to continue to participate with the project in a variety of roles, for example, as interviewer, as interviewee, or to continue as a reviewer in refining the survey instrument. A final draft of the instrument was mailed to three consumers and three service providers who attended the October 17th meeting at the Denver Indian Center, and who agreed to critique the instrument after changes from this meeting had been made. In addition, this version of be instrument was mailed to all key administrators and advisory personnel related to the



project (See Appendix D). An interviewer of the Pueblo study mentioned above was asked to critique the questionnaire based on his experience in interviewing Indian people who have disabilities. Feedback from 12 persons was obtained; in most cases, feedback was given in the form of revisions written directly on the instrument (See Appendix D for those letters received).

Pilot-testing the instrument. Two persons who had attended the working group meetings at the Denver Indian Center were asked to participate in the project as pilot-test interviewers. They were trained in interviewing techniques and use of the survey instrument during a two-day training held at Northern Arizona University on November 28 and 29, 1989 (See Appendix E). The training included video-taping practice interviews; critiques of the interviews resulted in further instruction and practice in using the survey instrument. The practice interviews took approximately 75 minutes each to complete. The following issues were raised by the pilot-test interviewer trainees:

- 1. Time must be taken to establish rapport with the family (if family is at home) before the interview with the individual begins. It was suggested that it might be particularly important to show respect for the position of the husband or father, as well as for any elders. The value of using humor to establish rapport and to facilitate the interviewing process was also noted.
- 2. Concern was expressed by both trainees that strong emotions could be released during the interview. For example, the "simple" statement "Please describe your disability" resulted in a very emotional experience for both trainees while being interviewed. It was agreed that common courtesy at a minimum should be used by the interviewers, for example, stating "Thank you for sharing that with me;" however, it was stressed that the interviewers were not being trained as therapists or even as problem-solvers. The trainees were instructed to call the Principal Investigator if they became concerned about the welfare of an interviewee. However, it was also stressed that the trainees were not expected to provide services to the individual. Based on this discussion, it was agreed that leaving a



services information packet or, at a minimum, a handout describing relevant services, would be appropriate.

3. At the conclusion of the training, both trainees expressed concern regarding the amount of work which was expected of them, especially in relationship to the amount of money they would be paid.

Pilot-test interviews were scheduled to be completed December 15, 1989; however, as one of the pilot-test interviewers decided not to participate, the deadline date was extended to December 22. All pilot-test interviews were completed by Sister Marie-Therese Archambault, who was subsequently hired as the on-site coordinator of the project (See Appendix F). Perhaps due to the comprehensive review of the instrument by both consumers and service providers prior to the pilot-test, very few changes were made to the instrument as a result of the pilot-test. Some items were rearranged to produce a more logical flow of questioning; one or two items were re-written for clarity. One or two response choices were also re-written based on feedback from the pilot-test interviewer [A copy of the survey instrument, the Consumer Interview, is available from the AIRRTC].

Procedure

With the completion of the pilot-test, the focus of the project turned to the hiring and training of interviewers. With the assistance of Arlen Rhoads, Director of Employment and Training at the Denver Indian Center, and Sister Marie-Therese Archambault, the on-site project coordinator, 11 persons were identified to be trained as interviewers (See Appendix G). In some cases, interviewer trainees had been involved in the project from either the initial advisory meetings and/or from the "working group" meetings. All interviewer trainees were American Indians. The training for interviewers was held January 9-11, 1990 at the Denver Indian Center (See Appendix H). Persons who were interested in being hired as interviewers were required to attend all three days of training [The Interviewer Manual is available from the AIRRTC; see also, Fowler, 1984]. The goals of the training were to explain the background and the purpose of the study to the interviewer trainees, to



instruct them on use of the instrument when conducting the face-to-face interviews, and to explain what recordkeeping was expected of them. The style of the training was interactive, with trainees contributing suggestions as to how interviews should be conducted, what additional questions should be asked, and giving feedback as to how they were affected by the interview process. For example, in terms of questions to be asked, the trainees recommended that while they believed it was important to ask about "American Indian illness" and treatment, it was extremely important not to probe in these areas.

After practice sessions where trainees interviewed each other, several concurred with the pilot-test trainees that strong feelings could be evoked when asking about disability and functional limitations; as one trainee remarked, "Until she started asking me all those questions, I didn't realize how messed-up I was." The importance of using native language when requested was also confirmed by the trainees. For example, one trainee, in the role of the interviewer, remarked how flat the affect of the interviewee was when questions were asked in English; she further commented, "When I use Sioux, I can see the answer on her face."

Percentage of agreement. In order to be hired as an interviewer, each interviewer trainee was required by the end of the training to demonstrate competency and reliability in using the instrument by achieving a percentage of agreement score of at least 80% (Borg & Gall, 1983). During the afternoon of the third day of training, the on-site coordinator (who had conducted the 10 pilot-test interviews) interviewed consultant Barbara Bradford using selected portions of the Consumer Interview. The interview was observed by the interviewer trainees who recorded the responses to the interview. Immediately following the interview, items were checked for correctness. Where responses were recorded incorrectly, retraining occurred. Percentage of agreement scores for each interviewer trainee were obtained by dividing the number of responses recorded correctly by the total number of possible correct recordings (n=289). Percentage of



agreement for those trainees hired as interviewers ranged from 94.5% to 99.7%, with the mean percentage being 97.9%.

Reliability and accuracy of recorded responses was further ensured in that each person hired as an interviewer was observed by the on-site coordinator when conducting one of his or her initial interviews; feedback was given immediately following the interview, or even during the interview if necessary to correct the way in which a question was asked or recorded. For example, in the case of one interviewer, it was determined that the "Consumer Concerns" section of the survey instrument was being presented incorrectly and corrective feedback given. However, subsequent analysis of the completed interviews indicated that the interviewer had continued to present the section incorrectly. As a result, 16 interviewees were mailed the "Consumer Concerns" section, with instructions on how it was to be completed (See Appendix I); 14 were returned and included in the data analysis.

Interviewers. Of the 11 persons who participated in the training, 8 were subsequently hired as interviewers. The average age of the interviewers was 39.8 years [Range = 29-60]; the majority [n=5(62%)] were female. Tribal affiliations were Navajo, Northern Arapahoe, Pawnee, Pima, Oglala Sioux, Standing Rock Sioux, Cheyenne River Sioux, and Three Affiliated Tribes. Three of the persons hired were also employed full-time in a human services/health related field; two were employed part-time. Four persons spoke their native language. All had at least a high school diploma or a GED; two persons had a bachelor's degree, while two were students in an undergraduate human services program. One person had a master's degree in a human services field.

Conducting and verifying interviews. John Compton, Assistant Executive Director, Denver Indian Center, Inc., agreed to be available to interviewers and to the onsite coordinator to handle emergency administrative concerns related to the project; Vera Mitchell, Department Director, Community Health Services, Denver Indian Health and Family Services, agreed to be available to interviewers in the event they encountered a clinical emergency, for example, evidence of elder abuse, when conducting an in-home



interview. Both the Denver Indian Center and the Denver Indian Health and Family Services offered their facilities for interviews or meetings of the project on an as-needed basis.

The Denver Indian Center, the Denver Indian Health and Family Services, the Colorado Rehabilitation Services, and a variety of additional service agencies in the Denver-metro area were sent flyers advertising the study in an attempt to recruit interviewees (See Appendix J). The on-site coordinator also contacted several service agencies and churches utilized by American Indians with disabilities, both in person and through flyers. Interviewers were asked to use their own informal networks to identify potential interviewees; however, it was agreed that interviewers would not interview immediate family members, although they could interview extended family.

All interviews were assigned to interviewers by the on-site coordinator; interviewers were paid \$25.00 for each interview completed (See Appendix K). Of this \$25.00, \$5.00 was allocated for travel reimbursement. Where this was found to be inadequate, interviewers were reimbursed, upon request, at 24¢ per mile traveled. Interviewers were also reimbursed, upon request, for incidental expenses incurred in conducting the interview. For example, interviewers were reimbursed for coffee or snacks they may have purchased in order to allow the interviewee to feel more comfortable during the interview.

In terms of interview assignment, while geographic location was taken into consideration whenever possible, interviews were also assigned on the basis of which interviewer was available to conduct the interview, and whether or not the interviewer had specifically requested to interview a particular individual. Interviews were to be conducted in a location comfortable to the interviewee and safe for the interviewer; a "base camp" for interview operations was made available to the project at the Denver Indian Center (See Appendix L). At the time of the interview, each interviewee was given a "Resources Information Packet" consisting of flyers from local agencies serving people with



disabilities. In appreciation for their time, interviewees were mailed a check for \$20.00 approximately four to six weeks after the interview.

Interviews were conducted from mid-January 1990 through mid-March 1990. Originally, the timeframe for conducting interviews was one month following the interviewer training. However, due to difficulties encountered in identifying American Indians with disabilities, the timeframe was extended an additional month. Difficulties included obtaining few referrals from the key service agencies involved in the project; many of the persons interviewed were identified through the informal networks of the interviewers. In addition, many of the interviewees (n=21) had neither a home nor a "contact" telephone, which made it a time-consuming process for interviewers to arrange an appointment. Even if a "contact number" were available, this meant calling a friend or relative of the interviewee, suggesting an appointment time, then re-calling the friend or relative to confirm the appointment after he or she had had an opportunity to speak with the interviewee.

Approximately 10% of all interviewees (n=10) were randomly selected [If he or she did not have a telephone, another interviewee was selected.] to undergo a verification process (See Appendix M); the Principal Investigator spoke with each of the 10 individuals called. Of those, 90% reported that their interviewer was courteous, with 100% reporting that the interview seemed relevant to their concerns. Comments made to the Principal Investigator included, "There is not enough help for Indian people," "There are services out there, but they are so hard to find; people don't offer the information," and "There are a lot of Indians who are not receiving help."

Conducting public meeting. A meeting regarding this project and open to the public, was held on the evening of April 17, 1990 at the Denver Indian Center; the agenda for the meeting can be found in Appendix N. The agenda was developed in collaboration with the project interviewers and with consultant Barbara Bradford (See Appendix O). The



interviewers, for example, expressed the desire to have their experience and concerns as interviewers presented by fellow interviewer, Susan Davis.

According to Fawcett, et al. (1988):

The town meeting is a critical component of the Concerns Report Method. . . . [It is] usually led by consumers with support from staff of local sponsoring organizations. In the town meetings, people share their experience on each issue, identify and discuss dimensions of the problems, brainstorm alternatives, and plan strategies to promote change. Participants see that their own experiences are not unique and that they can work together to solve common concerns" (p. 18).

At the recommendation of key project advisors and the on-site coordinator, the AIRRTC advertised the public meeting at the 16th Annual Denver March Pow Wow at a booth shared with the Social Security Administration. The flyer announcing the public meeting, which was distributed at the Pow Wow, can be found in Appendix P, along with an article appearing in a major Denver newspaper, the Rocky Mountain News. Each interviewee was mailed the flyer announcing the public meeting approximately three weeks before the meeting. In addition, key service providers in the Denver metro-area were mailed a letter briefly explaining the study and announcing the public meeting (See Appendix P). As the purpose of the meeting was to both share the results of the study with the community of American Indians with disabilities as well as to elicit from them additional data in terms of their recommendations for community change, it was decided by project staff and advisory personnel to keep invitations to service providers to a minimum.

Approximately 50 people attended the meeting, primarily service providers and individuals who had been involved with the research project as either advisory personnel and/or as interviewers. While 93% of the interviewees reported that they would be interested in attending the public meeting, very few were in attendance. The recommendation from interviewers that each interviewee be called and reminded of the meeting was not followed due to concerns regarding confidentiality. A partial list of



service providers who attended (those leaving their names) can be found in Appendix Q. The events of the public meeting were recorded on videotape; following are comments made both by persons on the agenda and by persons in attendance. The comments were selected for inclusion in this report due to their significance in pointing out the need for change, and for being representative of the tone of the comments made that evening.

After welcoming the community to the Denver Indian Center, the center's executive director, Mr. Wallace Coffey, described the programs and the activities of the center. He concluded by acknowledging the contribution of those who participated in the interviews, and stated that he would like to see the Denver Indian Center become a "one-stop shopping place for Indian people--from social services, to housing, to employment and training, adult education, and early childhood education. . . . Who knows, maybe around the corner we'll be able to address the needs of Native Americans with disabilities."

Consultant Barbara Bradford also addressed the group, stating that while "it's usual in our surveys that about 25% of people with disabilities work, the average income of the survey population was much lower than would be generally expected." She also commented that "on a national level, 70% of people with disabilities vote." and suggested that American Indians with disabilities need to "get out there and register to vote." Finally, she observed regarding the consumer issues identified in the survey as "problems" [See "Results" below], "out of the nine problems that you identified, seven of these have to do with not getting information, with attitudes, and with poor provision of services which do exist."

A major portion of the evening was taken up by a discussion between community members and service providers regarding the desire of community members to receive services from American Indian service personnel. For example, one woman commented: "My whole point was that . . . if once those applications came into your agency and . . . you knew they were Indian clients making the application, it would be nice if they were routed to the Indian personnel that you already have." Similarly, a young man stated:



I think that what the point was, was that there's generally a lack of trust for an Indian person going into a non-Indian agency. For myself, I'd rather go and talk to somebody with a brown face.... And if there were Indian people to talk with Indian people, then maybe more could be accomplished, and then your agency would be fulfilling it's task.... You've got to hire Indian people to help Indian people. Don't rely on the Indian Center.... Others are going to other places, but then doors are being closed on them. What do you do about that?.... You know, there are Affirmative Action programs, and truly, they should be followed. Hire people to help people; hire Indian people to help Indian people.... I'm sure yourself or anybody here--you didn't step into your job knowing everything that you know now. You learned it on the job--and that was it.

Personal testimony was given by one man regarding his experience in applying for benefits:

I had my medical records sitting right there saying that I'm blind. I'm functional, but I can't see you; I can see your shadows. So then there was this vocational rehab man there who said that I could carry sheltered work and be a, more or less, menial laborer and I was in school trying to better myself to become a professional man.... So now, it just makes me feel so bad what that white man told me. I've worked on SSI all year long just to let them say, "Hey, you're nothing; you're just a menial laborer." So that's what the whole situation is about—the social agencies, the systems, that look at Indian people like, "Your nothing; you're just a menial laborer." No, I've got education, I've got the intelligence, I've got the initiative, I've got the gumption to try to better myself, but the agencies are not doing anything.... And I'm blind. Thank you.

Finally, in describing the services of vocational rehabilitation, James Weiland, State Coordinator for Native American Programs, Colorado Rehabilitation Services, stated:



I believe that the Indian people, especially in the metro area, have been grossly underserved. I'm not going to point fingers at anyone; I think we all share responsibility to do something about it. That's why we are participating in this study No one agency can do it all themselves with the disabled folks in the community these days. . . . That focus that NAU is giving us--we need to take that ball and run . . .

The meeting concluded with Mr. Weiland's subsequent promise to talk with the Denver Indian Center's administration regarding the possibility of placing a state rehabilitation counselor at the center, as well as a call for more American Indians to pursue education in the field of rehabilitation counseling.

Recommendations regarding public meeting. Feedback from a key project advisory person regarding the small number of consumers at the public meeting included:

- 1. All interviewees should have been sent personal letters of invitation to attend the meeting instead of simply sending the flyer announcing the meeting to each interviewee.
 - 2. Interviewers should have called each interviewee personally.
- 3. As with the two previous community meetings held regarding the project, a dinner, rather than refreshments, should have been provided to signify the importance of the event.

Recommendations from the on-site coordinator regarding future research included:

- 1. Contacting interviewees to remind them to attend the public meeting should be a part of the job description of interviewers.
- 2. Interviewers should explain to interviewees at the time of the interview that they would be recontacted and reminded to attend the public meeting.
- 3. Interviewers should stress to interviewees that while the results of the interviews would be presented at the meeting, more importantly, it would be a time for the interviewees to make specific recommendations for change in their community's service delivery systems.



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Results

The results from the survey instrument are presented in the following order: General Information, Disability Information, Services Information (Formal Support Systems), Consumer Concerns, Educational Information, Social Information (Informal Support Systems), Employment Information, and Conclusions. Results include an analysis of both quantitative data as well as qualitative data. Where the number of persons responding to an individual item or question equals the population surveyed (N=100), only the percentage responding is given; where the number of persons responding to an individual item is less than 100 [For example, an interviewee did not give an answer to one of the questions], the number responding is given in brackets, with the corresponding percentage in parenthesis.

General Information

The majority of interviews [n=97; 68(70%)] were completed in the interviewee's home. Additionally, 14(14%) were completed at the Denver Indian Center, 3(3%) at the Denver Indian Health and Family Services, and 12(12%) at other locations such as a restaurant, a hospital, a library, and the Homeless Resource Center. A large majority of interviews [n=99; 92(93%)] were conducted in English, with 7% being conducted in a native language [Sioux (n=2); Navajo (n=1); Native Language not identified (n=4)]. In at least two cases, the interview was conducted in a mixture of native language and English, for example, Sioux and English. In each case where native language was employed, the interview was conducted by the interviewer; that is, an interpreter was not necessary as the interviewer spoke the interviewee's native language. Interviews took an average of 87 minutes to complete [Range = 40 minutes to 2 hours, 25 minutes]; 17% of the interviews took more than 2 hours to complete. [n=87; 15(17%)]

In all but three cases, the person interviewed was also the person who had a disability; exceptions included a parent, a sibling, and a wife who spoke for the person with a disability. The following discussion of demographic information refers to the person who has a disability; however, the term "interviewee" is used for convenience.



While all persons interviewed resided in the Denver-metro area at the time of the interview, two interviewees (2%) gave South Dakota as their permanent address. The largest proportion of interviewees lived in Denver County (67%), followed by Arapahoe County (15%), Jefferson County (8%), and Adams County (7%). The majority of interviewees were Sioux (See Table 1); 92% of all interviewees reported having a tribal census number, with 100% having a social security number.

Tribal Affiliation	Percentage
Ampahoe	1%
Cahuilla	1%
Cherokee	3%
Cheyenne	6%
Chickasaw	1%
Creek	1%
Creek Seminole	1%
Delaware	1%
Flathead	2%
Mescalero Apache	1%
Navajo	5%
Osage	3%
Paiute	1%
Ponca	1%
Sac and Fox	1%
Sioux	67%
Taos	2%
Winnebago	2%



Interviewees were almost evenly divided between males (45%) and females (55%), with an average mean age of 46.5 years [Range = 23-691] The majority of the survey population (51%) was over the age of 45, with a plurality (36%) over the age of 50. The marital status of the interviewees was evenly divided between those married (27%) and those divorced (27%). An additional 22% were either never married or single, 12% were either widowed or widowers, and 3% were separated; 9% did not identify their marital status. The majority of the interviewees were registered voters in both their tribes (55%) and in counties of residence (51%). The mean annual income of interviewees was calculated to be approximately \$6,086; however, the majority [n=97; 56(58%) reported

earning less than \$5,000 annually (See Figure 1). Figure 1 Range of Interviewee Income 3.09% 5.15% 8.25% 57.73% 25.77% \$0-4,999 \$5,000-9,999 \$10,000-14,999 \$15,000-19,999 \$20,000 & Over Note. n = 97



On the average, interviewees reported having lived in the Denver-metro area for 18 years [Range = 1 to 54 years]. Frequently reported reasons for living in Denver included: employment (25%) [Several persons mentioned "relocation."], the comment "This is my home, " or "I grew up here" (19%), "family lives here" (15%), services/treatment (15%), and "I like Denver" (11%). A large majority (89%), reported having previously lived on a reservation or in another community; of these individuals, 54% had lived in South Dakota, 8% in North Dakota, 4% in New Mexico, and one or two individuals each in Arizona, Oklahoma, California, Nebraska, Montana, and Nevada. For those persons who have lived in areas other than Denver, the average length of time most recently spent in Denver was 11 years. The majority of persons interviewed (62%) reported that they plan to always live in Denver. Frequently reported reasons for staying in Denver included: "This is my home" (18%), employment (16%), family (13%), "I like Denver" (8%), and services/treatment (8%).

The survey population (100%) reported that they could speak English fluently, with 97% reporting that they could read English and 96% reporting that they could write English. Additionally, 59% reported being able to speak their native language fluently. Of these individuals, 78% identified their native language as Sioux. A majority [n=99; 69(70%)], reported that primarily English was spoken in their homes; however, nearly a third of the population reported primarily speaking their native language (15%), or the combination of a native language and English (14%). A majority (72%) reported that they would prefer human service workers to use English when helping them, with a quarter of the population requesting that human service workers use either a native language (12%), or the combination of a native language and English (13%). Only 3% reported that it was not important to them what language human service workers use.

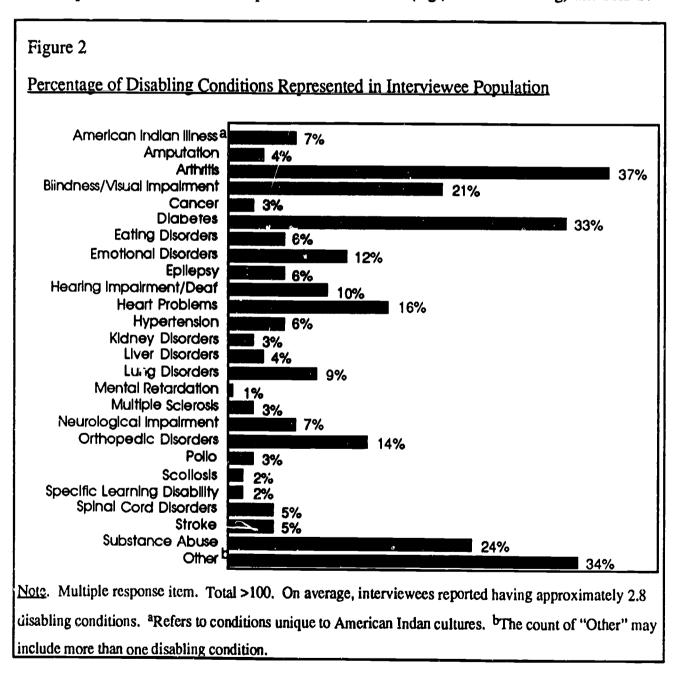
In terms of transportation, 44% of the survey population reported owning a car, with a slight majority (54%) having a driver's license. When asked, "What means of



transportation do you use the most?," interviewees primarily reported equal use of public transportation, that is, the city bus (37%), and their personal car (37%).

Disability Information

Disability conditions represented in the survey population are listed in Figure 2; clearly, this population is one which has multiple disabilities. Examples of disabling conditions, or chronic medication conditions, categorized as "Other" include atypical vertigo, chronic pain, herart murmur, complications of diabetes (e.g., skin not healing) and AIDS.



In terms of assistive devices and treatment, interviewees reported primarily using glasses (70%) and medication (68%) (See Table 2). Assistive devices classified as "Other"



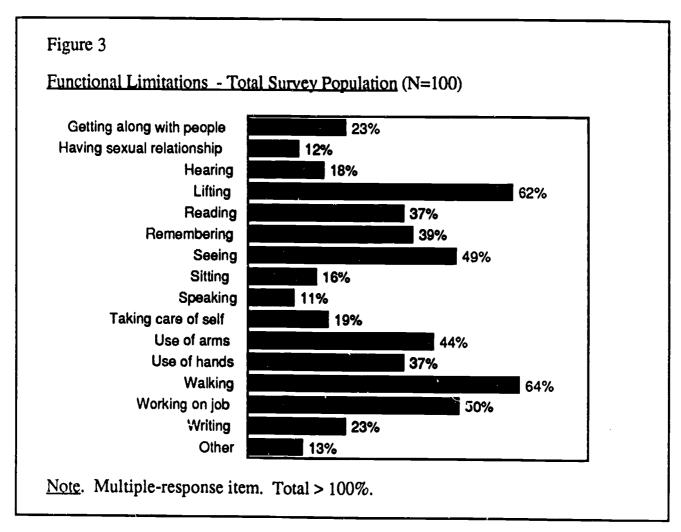
include, for example, dentures, oxygen, and orthopedic shoes. Similarly, the majority of interviewees also reported needing, or needing improved glasses (55%), as we'l as needing, or needing improved medications (17%) (See Table 2). Those interviewees who utilize medications as part of their treatment (68%), reported primarily taking medication such as insulin for diabetes and over-the-counter medication such as ibuprofen for pain; over a third of these individuals use three or more medications. Almost half of the redication users (44%) reported noticing side effects; for example, 20% reported that the medications made them feel drowsy and 10% reported they felt dizzy. Other side effects reported included dry mouth, stomach pain, water retention, and headache.

Assistive Devices/Treatment		Use Currently Improved	Need/Need	
(1)	Cane/Crutches	22%	6%	
(2)	Wheelchair	7%	4%	
(3)	Glasses	70%	55%	
(4)	Braille	0%	1%	
(5)	Sign Language	1%	2%	
(6)	Lip Reading	1%	2%	
(7)	Walker	6%	1%	
(8)	Hearing Aid	3%	10%	
(9)	Prosthesis/Brace	11%	4%	
10)	Medications	68%	17%	
11)	Native Medicine Way	28%	3%	
12)	Other	8%	4%	

In general, a plurality of interviewees (41%) reported their health as "fair," followed by a third (33%) reporting their health as "good." Only two individuals (2%) reported

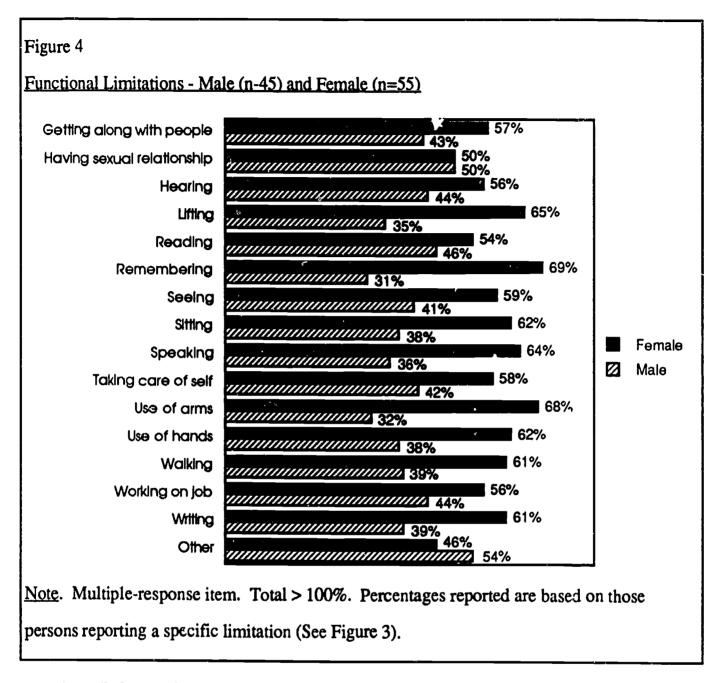


their health as "excellent;" almost a quarter of the population (24%) reported their health as "poor." In response to the question, "Does your disability limit you in doing the following activities?," a majority of interviewees reported functional limitations in key living activities such as walking (64%) and lifting (62%), with 50% reporting that their disability(ies) limited them in terms of working on a job (See Figure 3). Functional



limitations categorized as "Other" include for example, difficulties in: driving a car, sleeping, home repair, cleaning, and exercising. In almost all activities, female interviewees reported a higher proportion of functional limitation than did male interviewees (See Figure 4).





Services Information (Formal Support systems)

Interviewees were asked to report on the type of helping services they had received in the past year, to rate the helpfulness of each service, and to identify what agencies had typically helped the most in providing a given service (See Table 3). In addition, if interviewees had <u>not</u> received the service in question, they were asked whether they, in fact, had needed or wanted the service; interviewees who indicated that they <u>had</u> needed or wanted the service, but failed to receive it, were asked to identify the barriers that had prevented them from obtaining the service (See Table 4).



Table 3
Services Received in Past Year

	Service	% of Interviewees Receiving Services	Reporting Service as Helpful ^a			lost Helpful Agencies ^b
			n	%	n	Agency
1.	Coordination of Services	36%	(26)	71%	(7) (7)	DIHFS ^c State Social Services
2.	Help Receiving Food (n=99)	44%	(35)	79%	(11) (7)	DIHFS State Social Services
3.	Help Receiving Clothing (n=92)	26%	(18)	75%	(4)	DIHFS
4.	Help Receiving Housing (n=93)	25%	(17)	74%	(2)	Denver Housing Authority
5.	Help Receiving Benefits	64%	(47)	74%	(34) (14)	State Social Services Society Security
6.	Instruction in Daily Living Activities	9%	(6)	66%	(2)	Private medical doctor
7.	Vocational Training (n=99)	23%	(18)	78%	(3)	Denver Indian Center
8.	Medical Care	81%	(65)	80%	(17) (7) (2) (2)	Private medical doctor Denver General Hospi Stout Street Clinic Colorado Health Sciences Center
9.	Dental Care (n=99)	31%	(23)	77%	(9) (3) (2)	DIHFS Denver General Hospi Private Dentist
10.	Individual or Family Counseling	28%	(22)	79%	(6) (6)	DIHFS VA
11.	Alcohol Treatment	20%	(16)	96%	(7) (4) (2)	Eagle Lodge VA AA meetings
12.	Drug Treatment (n=99)	4%	(3)	75%	(3)	Eagle Lodge
13.	Legal Assistance (n=99)	8%	(6)	76%	(2)	Private attorney

Note. N=100 unless otherwise indicated; % based on "n" of item.

^aIncludes ratings of "Helpful" and "Made my problems much better;" actual number of interviewees reporting service as helpful is in parenthesis. ^bActual number of interviewees identifying agency as most helpful is in parenthesis. ^cDenver Indian Health and Family Services.



Table 4
Services Needed in Past Year but Not Received

Services		% of Interviewees Needing but Not Receiving ^a		Barriers ^b		
		n	%	n	%	Barrier
1.	Coordination of Services	(34)	53%	(13) (6) (6)	38% 18% 18%	Service not offered No transportation Could not afford
2.	Help Receiving Food	(20)	36%	(12) (3)	60% 15%	Service not offered No transportation
3.	Help Receiving Clothing	(2.5)	37%	(12) (6)	60% 24%	Service not offered No transportation
4.	Help Receiving Housing	(27)	39%	(15) (6)	56% 22%	Service not offered No transportation
5.	Help Receiving Benefits	(19)	53%	(8)	42%	Service not offered
6.	Instruction in Daily Living Activities	(14)	15%	(8) (3)	57% 21%	Service not offered Not well enough to use
7.	Vocational Training	(23)	30%	(13)	57%	Service not offered
8.	Medical Care	(9)	47%	(3) (3)	33% 33%	No transportation Could not afford
9.	Dental Care	(41)	61%	(14) (11)	34% 27%	Could not afford Service not offered
10.	Individual or Family Counseling	(12)	16%	(7) (2)	58% 17%	Service not offered No transportation
11.	Alcohol Treatment	(11)	14%	(3) (1)	27% 18%	Did not want to use No transportation
12.	; Treatment	(6)	6%	(2)	33%	Service not offered
13.	Legal Assistance	(7)	8%	(2)	29%	Could not afford

Note. Multiple-response items; total may be > 100%. a Actual number of in erviewers needing service is in parenthesis. b Barriers listed are those most frequently cited by interviewees.

The majority of interviewees reported receiving, in the past year, medical care, as well as assistance in receiving benefits such as food stamps. In each case, for those who received services, a large majority found the service to be helpful. However, in many



cases, interviewees reported needing a service, for example, dental care, but not receiving the service. Specifically, 61% of those interviewees who needed dental care (n=67), or 41 individuals, were not able to see a dentist. Typical explanations cited as to why a service was not received included the fact that the service was not offered to the individual and the fact that he or she did not have transportation to the service.

At the time of the survey, close to a third of the interviewees were receiving services from private medical doctors, the State Division of Social Services, the Social Security Administration, and through Medicare or Medicaid (See Table 5). Only two persons were receiving services from the State Division of Vocational Rehabilitation, Colorado Rehabilitation Services. Programs providing assistance which were not listed on the survey instrument, but which were identified by interviewees and categorized as "Other" on Table 5 include, for example, the Stout Street Clinic, Alcoholics Anonymous, Denver General Hospital, University Hospital, Humana Hospital, and the Homeless Resource Center. In response to the question, "Are there any other things you are doing now to help with your disability?", a plurality (29%) responded that they participated in some form of exercise, for example, walking.

In response to the question, "What services would you like to have available to you that you don't get now?," 14% responded that they needed transportation, for example, to keep medical appointments. Additionally, 14% stated that they would like to see changes in the medical services which they received, for example, financial assistance in buying medications, and being able to attend a clinic where they would see the same physician each time they went. Dental services were the next most frequently cited service needed (11%).

Finally, interviewees were asked to indicate what resources had given them "the most helpful information about services that can help you with your disability." The survey population cited: Friends (26%), Relatives (11%), Denver Indian Health and Family Services (9%), the Television (8%), the Newspaper (7%), and Denver Indian Center (4%).



Table 5

Percentage of Interviewees Currently Receiving Services (N=100)

Person or Program Providing Assistance	Percentage
Medicaid/Medicare	32%
Private Medical Docto	30%
State Division of Social Services	29%
Social Security Administration	28%
Native Medicine Way	23%
Sweat Lodge	18%
Denver Indian Health and Family Services	16%
Your Church	16%
Denver Indian Center	14%
Senior Citizens Program	9%
Veterans Affairs Administration	9%
Indian Health Services	6%
Catholic Community Services	6%
Eagle Lodge	5%
Psychologist	5%
Alcohol Counseling Program	4%
Mental Health Program	3%
State Division of VR	2%
Craig Hospital	2%
School	1%
State Division of DD	1%
State Job Service	1%
Other	12%



Consumer Concerns

A major portion of the survey instrument consisted of 40 issue statements also referred to as "Consumer Concerns." The data resulting from these issue statements caix be found in Appendix R. It is important to note that only those issue statements were subjected to analysis for which both a rating of "satisfaction" and a rating of "importance" were obtained. Items to which the interviewee responded "I do not know if this service is available" were, therefore, not included in the data analysis. The issue statements in Appendix R are listed in order by the mean percentage of satisfaction, with percentage of satisfaction ranging from 29% to 64%. Mean percentage of importance scores are also given, with percentage of importance ranging from 74% to 94%.

According to Fawcett, et al. (1987), a key component of the Concerns Report Method includes:

A summary of strengths (i.e., items with high importance and high satisfaction ratings) and problems (i.e., items with high importance and low satisfaction ratings). Strength scores are computed using the following formula:

S[Strength] = I x S {where I is the importance score and S the satisfaction score}. Problem scores are computed using the following formula:

P[Problem] = I (I-S) (p. 10).

Relative strengths of the Denver-metro area are listed below in Table 6. Relative problems are listed in Table 7. Any issue that is more than one standard deviation from the mean in either category is considered a top strength or a top problem. Data presented on Table 6 and Table 7 and found in Appendix R, were analyzed by staff of the Research and Training Center on Independent Living, The University of Kansas.



Table 6

Consumer Concerns - Relative Strengths of Denver-Metro Area

Item#	Survey Question	Average Importance	Äverage Satisfaction
31	Accessible parking spaces (i.e., handicapped parking) are available and adequate.	88%	63%
7	Landlords respect tenants' privacy, culture, and property.	93%	58%
37	Opportunities for adults to learn reading and writing are available.	92%	59%
25	Practice of proper nutrition (e.g., with people who have diabetes) is stressed.	90%	60%
1	Support and assistance are available from family friends, and neighbors to care for a disabled family member.	87%	62%
6	The physical design of the place you live allows you to be independent.	87%	62%
39	Adequate educational opportunities are available to you.	89%	59%
38	Special services in your schools provide good assistance for students with disabilities.	88%	60%
34	Access to other (e.g., Christian) religious services is available.	79%	63%



Table 7

Consumer Concerns - Relative Problems of Denver-Metro Area

Item #	Survey Question	Average Importance	Average Satisfaction
12	Social agencies have outreach services to contact all American Indians in the community who have a disability.	93%	31%
20	You know your rights (regarding e.g., housing, employment, social services) as a disabled citizen.	94%	34%
16	Local media provide education and adequate information for American Indians who have disabilities.	87%	29%
11	Social agencies inform you of benefits and services for which you qualify.	93%	35%
19	Advocates network to gain community support for issues related to American Indians with disabilities.	90%	33%
15	Social agencies inform you about <u>legal issues</u> related to disability and independent living services.	85%	34%
13	Examinations to assure the proper fit of an assistive device (e.g., wheelchairs, braces, hearing aids, glasses) are available at an affordable price.	92%	41%
10	Social agency staff treat you with dignity and respect given your cultural background.	92%	42%
4	Affordable housing (both private and public) is accessible to all types of disabled residents.	86%	38%



Educational Information

A plurality of the survey population [n=95; 37(39%)] have obtained at least a high school diploma, with an additional 13% having obtained a GED. Of those individuals not completing high school (n=29), the average amount of eduction received was 8.7 years. In terms of higher education, 16% reported having attended a college or university. However, 3% reported obtaining an AA Degree, and 6% reported obtaining a Bachelor's Degree. No one reported having a graduate degree.

Eleven percent reported having participated in special education. Of this population, three persons reported being in special education for all grades, K - 12; the remaining eight persons typically attended special classes for three or four grades. When reporting special classes attended, interviewees were evenly divided between those who needed special assistance with all subjects (n=5), and those who needed one or two subjects (n=5), typically, reading and writing or reading and math.

A large majority of the population (78%), reported that they would like to increase their education level. Of these individuals. 8% reported wanting to obtain their high school diploma or GED. An additional 13% wanted to pursue basic studies, for example, in the areas of reading and writing; an additional 13% wanted to continue their education in a human services related field, for example, counseling. Eight percent were interested in business, with 6% interested in math. An additional 6% were interested in computers, including word-processing. In response to the question, "Would you relocate to receive additional education or vocational training?" (n=98), 49% answered affirmatively; 51% reported that they would decline to move. Of those individuals willing to relocate, areas to which they would move included primarily western states (48%), for example, Arizona, New Mexico, or California; however, 25% reported they would be willing to move anywhere.



Social Information (Informal Support Systems)

Interviewees were asked several questions regarding their families and living arrangements in order to better understand their informal support systems; that is, who is there to assist the interviewee in an emergency, or even to assist with routine, day-to-day living activities. The majority of interviewees (80%) reported having children, with a mean average of 3.6 children [Range = 2 - 7 children] each. The average age of male offspring was 23 years, with the average age of female offspring being 22 years; offspring typically continue to live in the Denver metro area.

Seventy-one percent (71%) of the survey population reported that they did not live alone; on the average, interviewees lived with 3.4 persons. In terms of specific family members, interviewees reported living with a mean average of 1.5 parents (n=11), 1.1 brothers (n=8), 1.4 sisters (n=5), 1 spouse (n=24), 1.5 grandchildren (n=11), 2.8 children (n=45), 1.4 nephews (n=5), and 1 niece (n=2). Additionally, one interviewee reported living with an aunt, and one with three grandparents. Five interviewees reported living with an in-law, and five with a friend or rocmmate. Fourteen percent (14%) of those interviewed reported needing childcare. Of these individuals, one used a private baby sitter, three used a social service agency, five relied on their family members, and five cared for the children themselves. The majority of interviewees [n=99; 74(75%)] reported having a relative with a disability or long-term illness, most typically, diabetes [37(50%)]. The majority [n=99; 51(52%)] reported having either face-to-face or telephone contact with an immediate family member every day during the past year. A plurality [n=99; 34(34%)] reported having either face-to-face or telephone contact with an extended family member once or twice a month in the past year.

In terms of living accommodations, 41% of the interviewees lived in a house, and 37% in an apartment, with 22% reporting "Other" living arrangements such as a duplex, a trailer, public housing, or a shelter. Of those living in a house (n=41), the majority (51%) rent. Fifteen of the 100 individuals interviewed reported owning or buying his or her



home. Eight individuals reported living in a house with family members, most typically parents. In order to obtain a measure of their satisfaction in the community and with their personal living arrangements, interviewees were asked to respond to nine "quality of life" statements (See Table 8). While the majority of interviewees appear to be comfortable with their personal living arrangements, they also report wanting to live somewhere else, and finding it difficult to access services.

_	entage of Interviewees in Agreement with Quality of Life State	ments (14=100)
	Quality of Life Statements	Agree/Agree a los
(1)	I like the number of people who live with me.	73%
(2)	It is difficult to get services when I need to.	55%
(3)	I feel safe from danger.	70%
(4)	If I could, I would live somewhere else.	58%
(5)	It is convenient to get my clothes washed, go shopping, etc.	80%
(6)	The people who live with me care about what happens to me.	83%
7)	I am happy where I live.	76%
8)	The people in the neighborhood are nice to me.	74%
9)	The people I live with make me feel comfortable.	80%

In response to the question, "Do you have a reservation that you consider home?," a large majority [n=91; 78(86%)] indicated that they did. The plurality of these individuals (42%) stated that they visited their reservation "once or twice" a year. Thirteen percent (13%) stated they visited "whenever I can," and 8% visited "at least three or four times" a year. Typical relaxation and entertainment activities reported include: Watching television



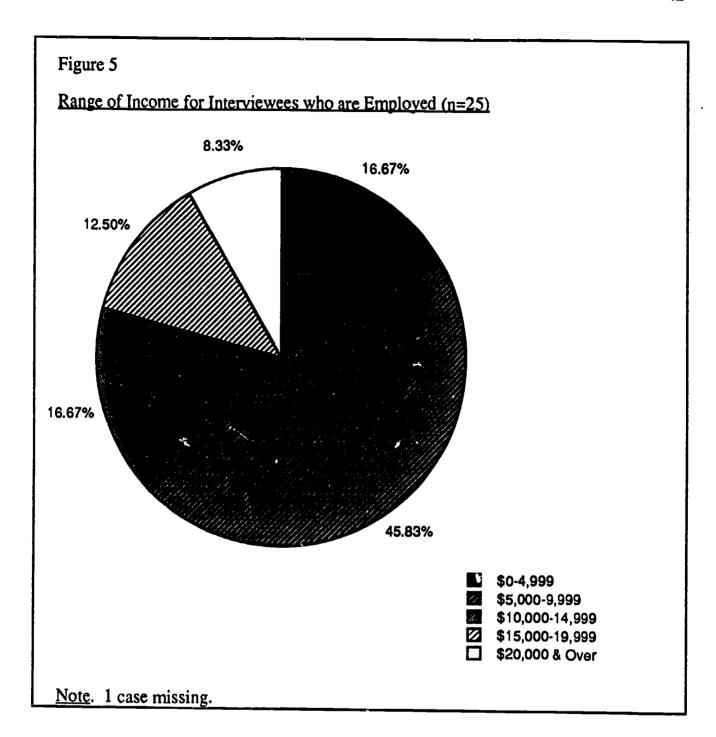
(18%), participating in sports or physical activities (14%), and participating in activities related to Indian culture (12%), for example, attending Pow Wows or beading. An additional 12% reported reading, followed by socializing with friend or family (11%), and watching movies (4%).

The majority of respondents [n=99; 69(70%)] stated that their income was not enough on which to live; a typical comment, for example, was: "We pay bills, eat, but cannot save." While 63% of the survey population reported being covered by some form of medical insurance or assistance, the majority of these individuals received coverage through Medicaid benefits [n=62; 33(53%)]. Additionally, 13% of those covered received health care through the Veteran's Administration, 10% through Medicare, 8% through public health services, 6% through private medical insurance, and 3% through the Indian Health Service. Eleven percent (11%) reported having more than one kind of coverage or assistance. Of those not having any type of coverage (37%), the majority (62%) stated simply that they "can not afford" medical insurance.

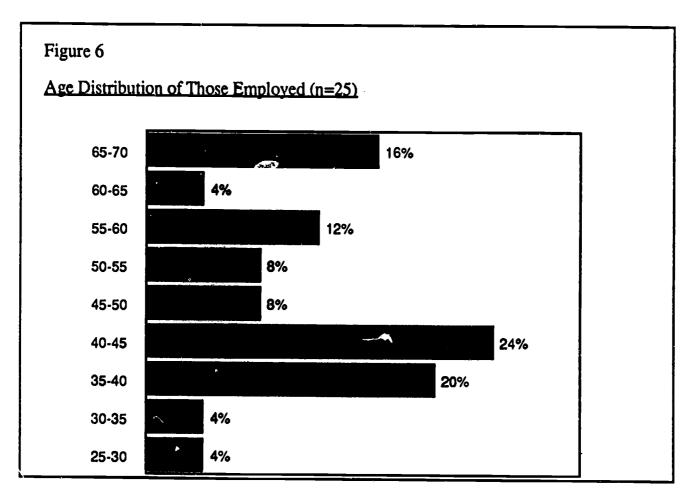
Employment Information

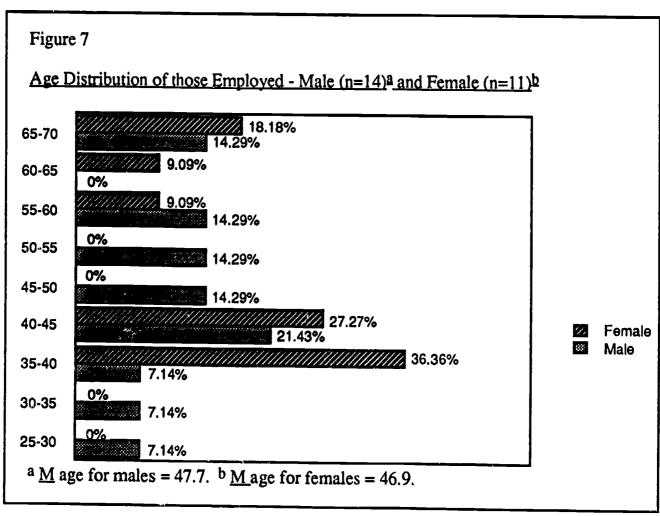
One quarter (25%) of the survey population reported working for pay; they earn a mean average annual income of \$10,139 (See Figure 5). These individuals have a mean average age of 47.3 years, with the range being from 27 to 67 years of age (See Figure 6). A plurality [n=4(36%)] of the employed women are between the ages of 35 and 40 (See Figure 7); the mean average annual income for employed women was \$11,250-somewhat higher than that of employed men, whose mean average annual income was \$9,346.













Positions held by employed interviewees (n=25) included: residential specialist for persons who have a developmental disability, health aid, nursing assistant, night manager, secretary (2 persons), janitor (3 persons), clerk (4 persons), maid (2 persons), postal clerk (2 persons), florist, seamstress, cook, minister, sexton, cashier, and office assistant. The majority of those individuals who are working reported being satisfied with their job [n=23; (18)78%].

The majority of interviewees reported that they are <u>not</u> looking for a job [n=98; 82(84%)]. Of those 16 individuals who are looking for work, four (4) are currently employed; these interviewees have been looking for a job, or a different job, for an average of 8.4 months. Interviewees typically reported looking for work through the newspaper (50%), the state job service agency (25%), and the Denver Indian Center (19%). One person each (6%) reported using the placement services of the Homeless Resource Center and Colorado Rehabilitation Services.

In response to the question, "What are your best job-related skills?," typical answers included: Clerical skills (15%), working with people in health or human services (12%), carpentry or construction skills (8%), cooking (6%), and janitorial skills (4%). In response to the question, "What kinds of jot's would you most like to have?," typical answers included: Working as a health or human services worker (19%), as a clerical or office worker (9%), in a skilled vocational trade such as a mechanic or electrician (9%), in management (5%), and in business or finance (4%).

The majority of interviewees [n=97; 58(60%)] reported that they have had problems finding a job; problems encountered are listed in Table 9. The majority of interviewees [n=99; 57(58%)] reported that they would not relocate for a job. For those who would relocate (n=42), preferred locations included western states (43%) or "anywhere" (21%).



Table 9 Problems Cited in Securing Employment (n=58) Problems Cited % n Because of Disability 28 (48%)Lack of Transportation 23 (40%)Lack of Money 19 (33%)Because of Ethnic Background 15 (26%)Home Responsibilities 14 (24%)Lack of Skills Required for Job 14 (24%)Employers Do Not Give Fair Chance 12 (21%)Because of Age 10 (17%)Lack of Appropriate Clothing 10 (17%)Lack of Job Availability 9 (16%)Because of Sex 6 (10%)Lack of Job-Finding Skills 5 (9%) Lack of Skills in Completing Applications Forms, etc. 4 (7%)Note. Multiple-response item. Total > 100%

Conclusions

In response to the question, "In general, how do members of your tribe view people with disabilities," 29% responded that the tribe in some way acknowledged them as "different," and provided services or help if necessary. For example, representative comments include, they "treat elderly and handicapped with respect," and "they care and try to help if they can." An additional 28% reported that they did not know how members of their tribe viewed people with disabilities. A small proportion of the survey population (10%) responded that their tribe viewed people with disabilities with sympathy or pity, followed by 9% who stated their tribe viewed this population "without much consideration" or attention.



Nearly all persons interviewed (93%) stated that they would be interested in attending the public meeting in Denver where results of this study would be presented; almost one-half of those interviewed [n=94; 46(49%)] reported knowing someone else in the Denvermetro area who had a disability. When asked, "Do you have any additional comments," several interviewees indicated that they hoped the survey would result in better services for American Indians with disabilities. Example comments include:

- ◆ "I wish someone could understand how we cope with our disabilities -- what we go through . . ."
- ◆ "I think more emphasis should be put on disabled Native American Vets. There are a lot of us Vets who don't know where to turn when we run out of our benefits . . .
- ◆ "Wished this survey would become a reality because Indians really need it bad."
- ◆ "I just hope all of this becomes a reality. Home health care and transportation for the Native Americans who really need it."
- ◆ "Being realistic, I would like for people to get these services [and] see my people go and get an education ... become doctors, lawyers, teachers."
- "I need a person to help me apply for Social Security disability, and I need help now."
- "Hope this all can work out for everybody. A lot of Indian people need help -- make this a reality."
- ◆ "I think it is going to be helpful to a lot people. It is very important that this survey is done and it's about time."
- "I wish that social services and private insurance firms would fund travel to see
 Native American healers."
- ◆ "With all this information, maybe the Navajo Tribal Council should address the health and medical issues facing Navajos in the Denver area."
- ◆ "I'm happy to see they are organizing something for Indian people -- this [survey] is badly needed. Most people don't have a concept of the Indian world."



- ◆ "I like what you're doing. It's never been done and a lot of Indians need help."
- ◆ "My disability is the kind that is not easily defined; therefore, I'm slipping through the cracks where services for the disabled are concerned . . ."
- ◆ "If we could get these services, it would be very beneficial to the Indian community and to myself."

Discussion

Of concern in generalizing the results of this study to other populations, including the population of all American Indians with disabilities in the metro-Denver area, is the fact that the survey population was not randomly selected, but a volunteer population obtained primarily through the networks of interviewers, and through Indian health and social service agency referrals. However, the survey population does appear to be representative of the larger urban American Indian population. In reviewing the literature related to urban American Indians, Weibel-Orlando (1982) concluded that, "Urban Indian communities are characterized by dispersed settlement patterns, extreme tribal heterogeneity, high mobility, connectedness to social ties on the reservations, continued dependence on kin assistance in social and political services, and familism" (p. 1). To some extent, this description also applies to the urban Indian community of Denver, Colorado, particularly in regard to dispersed settlement patterns, tribal heterogeneity, reported high mobility, and close ties to both reservation life and their families.

In addition, based on 1980 Census data, the Division of Program Statistics of the Indian Health Service ("Report of Urban Indians", 1988) has compiled demographic information regarding American Indians in the Denver-Boulder standard metropolitan statistical area (SMSA). [The inclusion of Boulder makes this area a bit larger than the metro-area in which this study was based.] There exists a slight majority of Indian males in the area (51%), with an average of 4.4 persons per family. A large majority (75%) are high school graduates. Median household income was reported to be \$15,794, with 8.2% of families living below the poverty level. The median age is 25. Similarly, in terms of the



survey population,-interviewees were almost evenly divided between males and females, with a slight majority being female (55%). They reported <u>living with</u> an average of 3.4 persons [The interviewee was not included in this figure.]; if the interviewee is added to the calculations, the average size of an interviewee household is also 4.4 persons. The survey population is older and less well educated than the Denver-Boulder SMSA population. Income levels can not be compared as this study reported individual income versus family income.

It is important to keep in mind that the total population of American Indians who have disabilities, and who live in the metro-Denver area, is an unknown population. That is, administrators from such service agencies as the Denver Indian Center, the Denver Indian Health and Family Services, the Colorado Rehabilitation Services, and the Denver Center for Independent Living agree the demographic characteristics of this population are unknown, the size of the population is unknown, and the needs of the population are unknown. Therefore, the results of this study will, hopefully, be useful to the policy makers, program planners, and service providers of Denver. As stated above, caution must be used in generalizing the results of this study involving 100 individuals to the total population; however, it is a beginning.

Specific concerns which can be identified from the results of this study include the age of the population. According to Weibel-Orlando (1982), "Indians who migrated to urban centers in the mid-fifties and remained to work . . . are currently approaching retirement age" (p. 2). Given that the majority of the survey population was over age 45, special services focused on the needs of an aging population, with multiple disabilities, may be warranted. Not surprising, given the age of the population, over a third reported having arthritis. A third reported having diabetes, and almost a quarter, problems with substance abuse. Of those reporting problems with substance abuse, over a third had orthopedic-related disabilities; the same number also had arthritis. The majority reported functional limitations in the basic activity areas of walking and lifting. It is of concern that



the vast majority of the survey population viewed their health as being only fair or poor, with 50% reporting that their disability(ies) limited their ability to work.

This aging, multiply-disabled population consistently reported having problems with transportation. Less than half of the interviewees own a car. A lack of transportation was frequently cited as a barrier to those needing, but not receiving services (See Table 4). Additionally, 40% of those reporting problems in securing employment cited lack of transportation as a factor (See Table 9). Transportation is clearly related to access. Given problems with transportation, it is not surprising that 55% of the survey population reported difficulty in accessing services in general (See Table 8).

Other access concerns include the lack of affordable housing (See Table 7); only 15% of the population surveyed own, or are buying, their own homes. Access to medical care is of concern given this population. While the majority do receive medical assistance or have medical insurance, almost a third of the interviewees reported being without either; quality of health care was not addressed in this survey. Areas in which interviewees were satisfied with access include the availability of: accessible parking spaces [handicapped parking], adult education opportunities, special education services in the public schools, and religious services (See Table 6).

The fact that only 25% of the survey population was employed is of concern. A comparison of Figure 1 with Figure 5 would indicate that employment appears to substantially increase the individual's income level, even though the majority of positions held are in service areas. Only 2% of the survey population reported currently receiving vocational rehabilitation services. Data provided by the Colorado Rehabilitation Services indicate that in the year prior to this study (July 1988 - June 1989), 44 American Indians were listed on counselor caseloads in the Denver-metro area. Of those, 14 persons (32%) were found to be ineligible for rehabilitation services; the cases of an additional 9% were closed before they were considered rehabilitated. Eight of the individuals (18%) had submitted an application, but eligibility had not been determined at the time of the report.



Four persons (9%) were considered rehabilitated, that is, working for at least 60 days during that year. As Weiland commented at the public meeting (See above), the state rehabilitation agency would appear to be underserving American Indians with disabilities in the Denver-metro area.

While all of the problems identified on Table 7 should be considered concerns, the lack of outreach from social service agencies appears to be of primary concern to the interviewees. This concern is substantiated by the frequency with which "services not offered" was cited as a barrier by those needing, but not receiving, services (See Table 4). In particular, regarding case management, or the coordination of services by a professional for persons with disabilities, of those who did not receive this service, 53% indicated that they did need the service (See Table 4). In terms of accessing information regarding services, the survey population reported depending primarily upon friends and relatives. Interviewees report comfort with the availability of their family and friends (See Table 8), and are satisfied with the support they receive from them (See Table 6). Interestingly, as regards accessing health care systems, Lewis (cited in Red Horse, Lewis, Feit, & Decker, 1978) has confirmed the importance of family and friends to urban American Indians, and suggested that the "sequential path" typically used in seeking help begins with the family network, followed by the social network, contacting a religious leader, the tribal community, and finally the mainstream health care system. Thus it would appear essential that outreach efforts by social service and rehabilitation agencies begin in the home, with families, versus, for example, only in health care facilities as pamphlets.

In terms of <u>culturally appropriate service delivery</u>, less than half of those surveyed felt satisfied that social agencies treated them with respect and dignity (See Table 7). The survey population appears to be predominantly a bicultural group of individuals, with commitment to both being Indian and living in the majority culture. For example, the majority are registered to .ote in both their tribes and in their counties of residence. The vast majority of interviewees (92%) reported having a tribal census number and a



reservation which they consider "home" (86%); however, the survey population has lived an average of 18 years in the Denver-metro area. The majority (62%) plan to always live in the Denver area. Everyone interviewed reported that they could speak English fluently, with a majority (59%) also being able to speak their native language fluently. Thus service delivery systems must be responsive to a population that can function in the majority society, but is grounded in Indian culture.

Only a third of the population surveyed reported being satisfied with advocacy efforts in the community (See Table 7). Similarly, the population was relatively unsatisfied with the amount of knowledge they had regarding their legal rights as citizens with disabilities, and with the amount of education and information regarding benefits and services available to them that is provided by social agencies and by the media (See Table 7). In many ways, the concern of the survey population with these issues leads to the question of self-advocacy, and their sense of each other as a community of American Indians who have disabilities. In defining "community," Liebow (1989) has stated:

We can think of a <u>social category</u> as a class of persons who share a set of specified personal attributes and interests. We can think of a <u>community</u>, on the other hand, as the people of a particular place who not only have shared attributes and interests, but who also jointly participate in furthering their collective interests. It is one thing to have something in common with others, it is another thing altogether to have something to do with people with whom one shares things in common (p. 30).

According to Higgins (1982), "One of the more obvious practical issues involved with the relatively small size of these urban [Indian] communities is the difficulty they have achieving political representation or developing planning consideration within a local system of government" (p. 14). Specifically, Higgins has stated that, "if one considers the Indian communities of Denver, San Francisco, or Minneapolis, the general problem of obtaining accurate, Indian statistics or developing a political-economic understanding, are also specific community issues today" (p. 18). Thus it would appear to reasonable that if



American Indians with disabilities are to experience improvement in their access to services and in the quality of the services they receive, it would be important for them to identify as a community.

Interestingly, the findings of this study focused at the community level are not unlike the findings of the AIRRTC (O'Connell, 1987) at the national level when researching the needs of American Indians with handicaps. Recommendations at the national level included the suggestion that "rehabilitation policy-makers and service providers should conduct outreach efforts as well as develop an increased capacity to serve those disability groups representing conditions of high prevalence within the American Indian population by the geographic location served" (p. 14). Recommendations also included the suggestion that there should be efforts to increase the employment status of American Indians who are disabled. For example, "rehabilitation counselors should increase efforts with American Indian VR clients to expose them to the world of work and provide information on occupational opportunities to which they may not previously have been exposed (p. 18)."

Commissioner Nell Carney (1989), Rehabilitation Services Administration, has stated that, "In the 1990's, Americans with disabilities will have the same choices as all Americans--choices in training, choices in employment, choices in politics, choices in recreation, and choices in full participation" (p. i). Will American Indians with disabilities in Denver, Colorado have these choices? Further, Commissioner Carney stated that, "the national rehabilitation network offers a full range of services, including independent living, prevocational training, supported employment, transitional employment, competitive employment, postemployment, and support and services to family members of the disabled person. These wide ranging rehabilitation services are offered as choices to people with disabilities" (p. i). Again, will American Indians with disabilities in Denver, Colorado have these choices?



Conclusions and Recommendations

Method be applied in a reliable, valid manner to address the need of American Indians who are disabled?," can now be answered. The answer is "Yes," given the modifications to the process presented above (See "Method"). In particular, it should be noted that the survey was conducted through face-to-face interviews versus through the mail. Also, while interviewers commented that some interviewees found responding to the 40 issue statements identified as "Consumer Concerns" tiring (See Appendix R), the results of this section of the instrument appear to be valid, and have been substantiated by responses to other sections of the instrument. Certainly, a key component of the Concerns Report Method, the "working group" utilized in developing the instrument, was an extremely successful component of this research. Another key component of the Concerns Report Method, the "town meeting," was somewhat successfully employed in this research-recomendations delineated above for improving the attendance of consumers at such a meeting will be implemented when this study is replicated.

Strengths of this research included the involvement of the Indian community, especially when developing the survey instrument. The personal interest of the persons hired as interviewers, and the on-site coordinator, contributed significantly to the success of the project. Unanticipated results of the study can also be considered strengths of the project. For example, one interviewee was nominated for an award by her interviewer; she won the award. Elizabeth Neva Standing Bear/Light in the Lodge was honored by the Colorado Women of Color for her history of achievement and community service (personal communication, September 7, 1990). Students hired as interviewers have asked for information regarding rehabilitation as a profession. Several of the interviewers have commented that they appreciated the opportunity this project gave them in terms of "access" to working with Indian people in the community.



Problems associated with this project include the fact that the face-to-face interviews constituted "labor intensive research." Interviewers drove (in the case of one interviewer, took the city bus) across metro-Denver (approximately 90 minutes from north to south and from east to west) during the winter months; snowstorms caused the cancellation or delay of more than one interview. Interviewees frequently had no telephone; at least one interviewer did not have a telephone. The decision to pay interviewees by check resulted in interviewees waiting more than a month to receive compensation for their time.

Interviewers were not compensated for their time when interviewees were not at home or difficult to reach; five cases of interviewees not keeping an appointment for an interview were documented by the interviewers.

Recommendations Regarding the Process of Research

Seven of the eight interviewers completed an evaluation of the project (See Appendix S); at the time of the evaluation, they had completed an average of 11 interviews, with a range of from 7 to 16 interviews. Lix of the seven (86%) agreed or strongly agreed that the interviewer training which they had received prepared them to conduct the interviews in an effective manner. Their recommendations for modifications of both the survey instrument and for the process of the research will be taken into account when this study is replicated. Specifically:

- 1. Expedite payment to interviewees; for example, pay in cash immediately following the completion of the interview.
 - 2. Expedite payment to interviewers.
- 3. Address compensation of mileage for interviewers; especially when interviewee is not at home.
- 4. Limit the "Consumer Concerns" section of the survey instrument to no more than 30 items.



- 5. Hold weekly meetings with the interviewers during the time interviews are conducted in order to answer any questions, review procedures, and allow them to network with each other. Interviewers would be paid for their attendance at the meetings.
- 6. Review policy of <u>not</u> having interviewers act as intervention agents. They reported seeing many people in need, and felt the "Resources Information Packet" distributed to interviewees was not useful in meeting immediate needs.

Recommendations for Change in Service Delivery

Recommendations for change in the Denver community are presented with caution, as they are based solely on the needs of those individuals surveyed. However, given the population data presented above, it seems reasonable to suggest that the population surveyed is not unlike the true population of American Indians with disabilities in the Denver-metro area. Reid, O'Neil, Manson, Lundberg, & Joe (1990), in commenting during a panel discussion upon the relationship of researchers to the Indian community, have stated that community-based research requires both accountability and respect for the community. However, they also agreed that "it is up to the community and to the tribe to take the information from research and develop culturally appropriate programming or follow-up." It is in that spirit that the following recommendations are made--the community may well find other directions in which to pursue change.

It should be noted that many of the following recommendations for change have been made, or have been implemented, at least temporarily, in Denver's recent history.

In March 1981, the Colorado Developmental Disabilities Council established a Committee for Concerns of Minorities with Developmental Disabilities; the Committee was charged with developing an outreach program which would be based at the Department of Social Services, Division of Rehabilitation (See Appendix T). A progress report, dated December 9, 1982, delineated the concerns of those charged with providing outreach to American Indians with disabilities. Interestingly, many of the issues which have been identified through this research as concerns, were also identified eight years ago as concerns. For



example, the report stated that "transportation is not available for handicapped or disabled persons to get to and from meal sites, service agencies, hospitals, [and] social activities." Further, "disabled persons [had an] inability to pay for services that are available." The final results of this outreach effort are unknown; the concerns remain. In order to address the concerns identified through this research it is recommended that:

- 1. In-home outreach to identify individual needs should be conducted by those agencies sincerely wishing to serve American Indians with disabilities. This outreach should be accomplished through the use of Indian case finders, and should be conducted under the auspices of a single agency, for example, an Indian health or social services agency, in order to avoid duplication of effort.
- 2. Case-management services should be available to ensure that basic needs are met. Interviewees consistently referred to problems with transportation, and accessing basic health care such as dental services. They need very basic assistive devices such as glasses. Client advocates should provide case-management services through Indian service agencies.
- 3. Vocational rehabilitation services, which focus on the special needs of an aging workforce with multiple disabilities, should be made available within the Indian community.
- 4. Increased employment opportunities must be made available. While 78% of those working (25% of the survey population, or 25 individuals) reported being satisfied with their current positions, increased levels of employment must be available to those who would want them.
- 5. American Indians with disabilities in Denver need to recognize themselves and identify themselves as a community. As a community, they can engage in self-advocacy activities, perhaps beginning with a drive to increase the number of American Indians with disabilities who are registered to vote.



- 6. Service agencies interested in the needs of this population can assist their community-building efforts through education and information programs focusing on their legal rights, in particular as regards employer accommodation to disability and accessibility issues.
- 7. Indian health agencies should develop education and information programs for the general Indian community which stress the "health and wellness" aspects of disability, and provide specific information for persons with disabilities on how to cope with their conditions in order to avoid, as much as possible, functional limitations.
- 8. Finally, the request of American Indians with disabilities to be served by American Indians can not be ignored. Service agencies in Denver must renew their efforts to train, hire, and retain American Indians to serve this population.

Issues Warranting Further Investigation

This research is only a beginning. Many more issues related to the needs of American Indians with disabilities must be addressed in the Denver-metro area, for example:

- 1. While efforts were made to include transition age youth in this research, interviewees ages 14-22 were not identified. Where is this population? Are the schools adequately meeting their needs? Are they working?
- 2. Are there differences in service delivery needs for those who are recent arrivals in Denver versus those who have lived in Denver all of their lives? Where do recent arrivals go first for assistance?
- 3. Shannon and Bashshur (1982) have defined "access" in terms of "convenience factors," such as travel time, appointment delay time, and waiting room time. Using this definition of access, how accessible are health, social service, and rehabilitation agencies to American Indians with disabilities?



C1 71

4. The results of this study indicate a disparity between men and women's income, and men and women's functional limitations. What special services, if any, should service agencies employ to address these disparities?

......

Note

A draft of this report was sent to 20 randomly selected interviewees for critique, as well as to project interviewers, staff from sponsoring agencies, and interested community members; their comments can be found in Appendix U. Critiques were obtained both in writing and through telephone conversations. Any critiques obtained through telephone conversations were typed by AIRRTC staff and mailed to the individual for confirmation. Written critiques were edited for typographical errors; personal communications to the researchers were deleted. Changes have been made in both the content and the format of this report as a result of the critiques.



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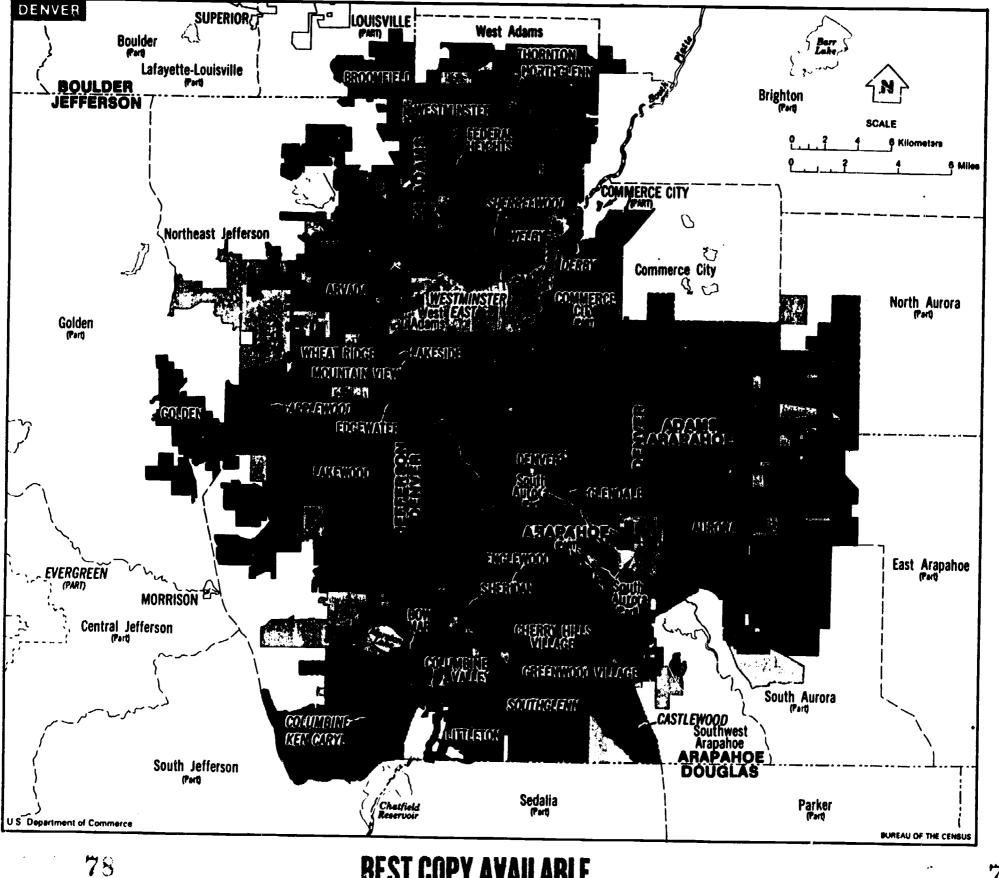
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Appendix A Denver Urbanized Area







Appendix B

Correspondence Related to First "Working Group" Meeting





American Indian Rehabilitation Research and Training Center



The American Indian Rehabilitation Research and Training Center will be conducting a survey in Denver, Colorado of American Indians who have disabilities. The purpose of this survey is to help persons with disabilities identify both the strong points and the problems in their community, meet to discuss issues identified in the survey, plan ways to improve the community for persons with disabilities, and present this information to decision makers and service providers in order to expand and improve services.

We would like to have your help in developing this survey, and ask that you attend our planning group meeting:

Tuesday, September 26, 1989 4:00pm - 7:00pm

Denver Indian Center 4407 Morrison Road

Buffet Dinner Provided

Please think of issues related to your own experience with disability--both positive and negative issues--and plan to share these issues with the group. We look forward to working with you!



-American Indian Rehabilitation Research and Training Center



Agenda

Consumer Concerns Survey Working Group/Advisory Meeting

Tuesday, September 26, 1989 4:00pm - 7:00pm

1) Welcome

4:00pm - 4:30pm

Wallace Coffey, Executive Director Denver Indian Center

Rockling Todea, Executive Director
Denver Indian Health and Family Services

2) Explanation of Research Project

4:30pm - 5:00pm

Marilyn Johnson, Executive Director American Indian Rehabilitation Research & Training Center Northern Arizona University

3) Facilitation of Working Group

5:00pm - 6:00pm

Barbara Bradford, Associate Trainer The Research and Training Center on Independent Living The University of Kansas

4) Buffet Dinner

6:00p.n - 7:00pm

Concluding Remarks
Collection of Information Sheets
(Demographic info re: working group members)
Announcement of second meeting--working group only (?)
Questions and Answers



American Indian Rehabilitation Research and Training Center



CONSUMER CONCERNS SURVEY Working Group Participant Information

Name		
Address		
City		Zip Code
Phone Number		
Are you particing has a disability		rself or for a family member who
Myself; my	y disc∵ility i	s
Age	Sex	Tribe
For a fami	ily member; my	family member's disability
is		
Age	Sex	Tribe
I represen	nt	(Service Agency)



Appendix C

Correspondence Related to Second "Working Group" Meeting





American Indian Rehabilitation Research and Training Center



October 11, 1989

Dear

Please find enclosed a copy of our draft questionnaire; items related to the issues which were identified at the meeting September 26 begin on page 16.

Please add items to the questionnaire, or take out items as you see fit. I included a lot of information on this draft just so we would have something to work from. Please bring the questionnaire to our next meeting Tuesday, October 17 at 6:00pm at the Denver Indian Center.

If you are interested in working as an interviewer on this project, please plan to also meet Wednesday morning, October 18 at the Denver Indian Center. We will decide on a time Tuesday night.

I look forward to seeing you soon.

Cordially,

Catherine A. Marshall, Ph.D. Research Associate/Associate Professor



Institute for Human. Development & Northern Arizona University P. O. Box 5630 & Flagstaff, Arizona 86011-5630 & (602) 523-4791

Appendix D

Feedback Letters Regarding Survey Instrument





-American Indian Rehabilitation Research and Training Center



November 1, 1989

Dear

Please find enclosed the Consumer Questionnaire which will be used to interview American Indians who have disabilities in Denver. The questionnaire has been developed with the input of persons with disabilities and service providers in two meetings held at the Denver Indian Center. I will appreciate your reviewing the questionnaire and suggesting any additional questions you would like to see included. Please be more concerned with the content of the questionnaire than with its format, as we are continuing to work on the layout. Please remember that this survey will be conducted as a face-to-face interview; if pilot testing indicates that it will take more than 90 minutes to complete, items will be deleted.

Please send your comments to me by Wednesday, November 15, 1989 to P. O. Box 30634, Tucson, AZ 85751, or call me at (602) 721-0991, ext. 624. I look forward to hearing from you. A self-addressed stamped envelope is included for your convenience.

Cordially,

Cathy

Catherine A. Marshall, Ph.D.

Research Associate/Associate Professor

Enclosure





DENVER INDIAN CENTER, INC.

4407 MORRISON RD. • DENVER, COLORADO 80219

Administration 936-2688 / 937-0401

Adult Education 936-2898

Circle of Learning 936-2688 / 936-2898

November 15, 1989

Employment Training 937-0401

Human Services 936-2688 / 936-2898

Senior Citizens 936-2688

Vision Quest 937-1005

Dr. Catherine A. Marshall, Ph. D P.O. Box 30634 Tucson, AZ 85751

Dr. Marshall:

Enclosed is a copy of Draft #3 of your Consumer Questionnaire along with my remarks, observations, and suggestions penciled-in. My questions may have already been answered by you previously but since my memory is faulty, I have included them.

Wallace indicated on his copy that the questionnaire looked good, consequently he did not have any further questions or suggestions.

Thank you for allowing us to participate in the construction of this questionnaire. So for whatever its worth run with it! Field test the sucker!

John H. Compton

Assistant Executive Director

cc: Wallace E. Coffey



Cicil W. Campbell 640 Brodway #49 Nerwir, Colorado 80203

Cathy 4. rishall PHD. P.O. Box 30634 Jucsur, ag. 85751

please find enclosed my return Courpandence.

- Several viry important questione:

 Als you have a suial security card?

 Be you have a lotorado identification?

 The 5.5. card is an suy important scarce of infromation for social service agencies.

 and I know for a fact that a summer

 of chaine do not know how to so about a social social social.
 - The Colorado I.D. also may be a problem for a Chief due to underlying factore of the law.
- pages No you speak your Hat in Language Thurthy?

 The language of speak and people of spoke too

 state that we can not carry on a conversation.

Page o Substance above is a divine terno in the sense it cover inhalists such various que, painte, hourspraye, gasoline etc.

Page 18. Friend de romate cultural hectiage.

Cuitnessed in the past several cliente refused
assistance deli to their friends or roomater

Thererage are to their frendship difference.

I give this my only response. I hope
it Contributes to the laws. So now I'll leave
if up to you and your staff for your considerations.
if look forward to hearing from you.

Cordiaily civil R. Camplusi

Enciosure:

I think austine putaining to Why dod you Meve to Buver? Should be scatisfed on.

In my situation. After I found my Visical impairment. I came to dienver seeking Vocational reliabilitation services cause I knew I could receive better services, employment is more abundant wages are higher, transportation is no problem, education systems are in the transportation reproduced in the provider of the transportation of the provider of

STATE OF COLORADO

DEPARTMENT OF SOCIAL SERVICES

REHABILITATION SERVICES

1575 Sherman Street, 4th Floor Denver, Colorado 80203-1714 Phone (303) 866-4390

ANTHONY J. FRANCAVILLA Associate Director Roy Romer Governor Irene M. Ibarra Executive Director



November 10, 1989

Catherine A. Marshall, Ph.D.
Research Associate/Associate Professor
American Indian Rehabilitation
Research and Training Center
Institute for Human Development
Northern Arizona University
P.O. Box 5630
Flagstaff, Arizona 86011-5630

Dear Dr. Marshall.

Thank you for the opportunity to review Draft No. 3 of the Consumer Questionnaire. In general, I think the instrument will provide a wide array of information, if all the questions receive appropriate responses. I hope the interviewer and consumer will be patient enough to answer all they can.

It might be helpful to add space for TTY/TDD numbers. While TTY's use the same line as a voice telephone, having the number listed separately can alert the caller to the need for a TTY when contacting the consumer. I suggest you add Traumatic Brain Injury, Muscular Dystrophy, Stroke and Spina Bifida to your list on pages 4 and 5. It might also be beneficial to spell out agencies, rather than using abbreviations, e.g., "DD" should be Developmental Disability, etc.. I think it would be worth while to ask a question like "...Before you moved to the Denver area, did you know what services might be available? If you did, who told you?"

Another question (related to SOla) could be "...When you need day care services for your children, where do you go to get it? How much does it cost? Are you able to pay for it? If not, who does pay?" I thought that many of the questions were get toward Independent Living concepts, so I have enclosed a list of categories for your perusal.

It will be interesting to see the outcome of your survey. Hopefully,, there will be appropriate services available after needs have been identified. Keep in touch.

Sincerely,

Jim Weiland

Dim Cheland

JW/sb Enclosures

ERIC

Full Text Provided by ERIC



The Research & Training Center on Independent Living

November 16, 1989

Catherine A. Marshall, Ph.D. P.O. Box 30634 Tucson, AZ 85751

Dear Cathy.

I have been trying to get in touch with you by phone. I had the surgery on my leg - it now has to be kept out straight and even using the PC to write is more hassle than usual and I am trying to get as much done by phone as possible. But - Maybe for the best - here it is in writing.

I received the survey. The demographics are much more extensive than any we have ever had, and far more than we need for our own cumulative database, although I can see why you want them and where you and the Native American RTC and Denver Center could make use of many of them. By the way, the concerns part of it looks great. Here is what I would propose for the demographics:

In terms of formation we store in our cumulative database, we only need one page of information in our particular format as far as demographics go. This would be disability, age, sex, education, employment status, income, registered voter (which I noticed you didn't ask - can you?), county and state of residence, and race. We don't need this information to the degree of detail in your proposed demographics.

You could retain your desired length and format if you had your own data entry people in Arizona enter and analyze your demographic section of the questionnaire. It might be less costly (I know we couldn't enter this proposed length and varied format for the usual 50 cents a survey) and would probably be more desirable to keep the demographic data at your disposal in a form you can use best.

The University of Kansas

BCR/3111 Haworth Lawrence. Kansas 66045-2930 (913) 864-4095 Voice/TDD



Catherine A. Marshall Page 2. November 16, 1989

One solution would be to attach the page we need to the survey for the interviewer to check off after the interview. I am enclosing a sample of what our page would be like. After completing the demographic section as you have it now, the interviewer should be able to check off our page by him or her self without even re-asking the questions in less than a minute. It might also work to pull your questions in these areas to the front of the survey and lead with them, rather than have them dispersed throughout the survey. It might also be of help to both of us, thinking in terms of doing similar surveys with other Indian populations both urban and reservation, to develop about a 2-page demographic summary to lead with, which would be consistent throughout all or most surveys done with Indian populations to start to develop a cumulative database. For example, in addition to the questions on our one page, you might have questions as to tribal affiliation, urban or reservation, living situation, use of DVR and IHS services, and other information which might be helpful to accumulate over a larger and more varied population over a length of time.

Although this is a golden opportunity to get a lot of useful information, and definitely should be used, don't lose sight of the purpose of the concerns report method which is to organize the consumers around their own issues to take their own actions and propose their own solutions. With this in mind, it might work best if the concerns area were asked first, and then the demographics. This would have the respondent thinking about issues before he or she became fatigued by a long interview, and might also have the beneficial effect of starting the interview on a note of reciprocal conversation and ideas rather than on responses to direct questions.

PAGE BY PAGE COMMENTARY ON DEMOGRAPHIC QUESTIONNAIRE:

In general, make sure you really need all the information asked. Is it really going to be useful? The comments on the survey in pencil are from my colleague Yolanda Suarez.

Page 2: Do you really need all the information in the box. Isn't GI12 enough

Page 3: Do you need GI27? Combine GI29 and GI30?

Pages 4 and 5: Try to combine and simplify disability info.

Page 6: On D13, do you need these questions as well as D12? If you do, you might add one about whether they have difficulty paying for the medicine or getting it provided.



Catherine A. Marshall Page 3. November 16, 1989

I like D14. I assume the answer to this is what the interviewee perceives to be his or her main problem. Good.

Page 7: I agree with Yolanda - just a yes or no answer is enough. Who provides the needed help might be interesting.

Pages 12-13-top of 14: Again, do you really need more than a yes or no answer?

Page 14: SI13 seems redundant - you have it covered in SI12x. SI14 add "that you don't get now.

Page 15 - I like it.

Page 16: Do you really need all this? Could it be condensed?

Page 17: Good relevant info.

Page 18: Are S01a and S02a necessary?

Page 19: S03 define "relative" to limit definition

Page 20: Aren't most of these covered in the concerns section?

Page 31: Just leave room for interviewee comments and interviewer comments.

Ask somewhere if the respondent is a registered voter 1) in the tribe 2) in general. Our surveys with the general population have shown 70% of people with disabilities to be registered voters - twice the national average. If this is the case, it's good info to have when you go to the legislature and other politicians. If it isn't the case, it's time for a voter registration drive.

I hope these and Yolanda's comments are helpful.

Sincerely,

Barbara Bradford

Training Associate





PUEBLO OF SAN FELIPE

TRIBAL CHR PROGRAM

October 26, 1989

Catherine A. Marshall P.O. Box 30634 Tucson, AZ 85751

Dear Cathy Marshall:

I enjoyed reviewing your superb job on the questionnaire to identify the needs of Native Americans with disabilities who live in an urban area.

I would like to be placed on your mailing list and have the opportunity to follow the progress of your research on Native Americans with disabilities.

Thanks and Congratulations.

Sincerely,
Withe Piners



Appendix E

Pilot Interviewer Training Agenda





AMERICAN INDIANS WITH DISABILITIES COMMUNITY NEEDS ASSESSMENT Denver, Colorado

PILOT INTERVIEWER TRAINING AGENDA

American Indian Rehabilitation Research & Training Center Northern Arizona University Flagstaff, Arizona November 28 - 29, 1989

DATE/TIME	TOPIC	TRAINER(S)
November 28		
9:00 - 9:30	Introduction Overview of Project	Marilyn Johnson, Ph.D. Director, AIRRTC
9:30 - 10:00	Overview of Training & Training Manual	Catherine Marshall, Ph.D. Research Associate, AIRRTC
10:00 - 10:15	BREAK	
10:15 - 11:30	Disability Information	Catherine Marshall
11:30 - 12:30	LUNCH	
12:30 - 1:30	Services Information	Catherine Marshall
1:30 - 2:30	Culturally Sensitive Interviewing Strategies	Marilyn Johnson
2:30 - 2:45	BREAK	
2:45 - 4:00	Review of Instrument & Training Manual	Marilyn Johnson Catherine Marshall
4:00 - 5:00	Interviewer Practice in Dyads	Catherine Marshall



November 29

8:00 - 12:00	Making of Demonstration Videos	Saravan Al Yardley Marie-Therese Archambault
12:00 - 1:30	LUNCH	
1:30 - 3:00	Critique of Videos	Al Yardley Marie-Therese Archambault Marilyn Johnson Catherine Marshall
3:00 - 3:15	BREAK	
3:15 - 4:00	Set-up pilot interviews	Al Yardley Marie-Therese Archambault
4:00 - 5:00	Wrap-Up	



Appendix F Job Description of On-Site Coordinator





JOB DESCRIPTION

Title: Research Technician IV (On-site Coordinator for AIRRTC Project R-20)

Prime Function:

Under the supervision of Dr. Catherine Marshall, performs work of considerable difficulty in directing or performing a wide variety of standard and specialized tasks on a research project.

Duties and Responsibilities:

- A. Training
 Tasks
- 1. Assists at Interviewer training workshop as needed on January 9 10 at the Denver Indian Center.
- 2. Provides supplemental training to interviewers as needed.
- B. Supervisory Tasks
- 1. Performs specific tasks related to conduct of research project on community needs assessment of individuals with disabilities in the Denver metropolitan community, e.g., assignment of interviewees to interviewers in collaboration with Dr. Catherine Marshall.
- 2. Assists interviewers with scheduling appointments with interviewees (individuals with disabilities or family members).
- 3. Assists with monitoring and verification of interviews and the professional conduct by interviewers, including the observation of at least one interview by each interviewer.
- 4. Assists the interviewers in submittal of project paperwork, e.g. invoices for payment.



C. Other Tasks

- 1. Will collect and compile information, brochures, pamphlets and other information regarding resources and services available to American Indians with disabilities in Denver area.
- 2. Maintains close communication with the Principal Investigator, Dr. Catherine Marshall and with the Executive Administration of Denver Indian Center, Mr. John Compton, and relays immediately any difficulty relative to the interviews or any other related issues.
- 3. When no other interviewer can carry through on a given interview, will complete the interview.

Knowledge and Skills:

Considerable knowledge of methods and techniques in research related to American Indians with disabilities.

Skill in personal relations.

Skill in written and verbal communication.

Supervisory and monitoring skills.

Minimum Qualifications:

Experience related to individuals with disabilities. Considerable experience in working with American Indians is preferred.



Appendix G

Correspondence Related to the Hiring of Interviewers
Interviewer Job Description





-American Indian Rehabilitation Research and Training Center



December 5, 1989

Mr. Arlen Rhodes, Director Employment and Training Denver Indian Center, Inc. 4407 Morrison Road Denver, CO 80219

Dear Mr. Rhodes:

Please find enclosed a copy of the "Interviewer Job Description" which we discussed during our recent telephone conversation. I would like to hire 10 interviewers and have had five or six persons express interest in the position; however, I have no firm commitments to date.

I would appreciate your help in identifying at least five persons who meet the qualifications listed in the job description. Please have each of the interested persons complete one of the "Interviewer Information" forms also enclosed. I will appreciate your returning these completed forms to me as soon as possible as we are planning our training for January 9, 10, and 11.

I intend to channel interested persons with whom I have had contact through your placement service, and will call you in the next week to clarify how this is to be done.

I very much appreciate your help in this matter. Please return the "Interviewer Information" forms to me at:

1816 E. Waverly Tucson, AZ 85719

My telephone number is: (602) 326-9064. Messages for me can be left at: (602) 523-4791.

Sincerely,

Cathuni A. Marshall

Catherine A. Marshall, Ph.D. Research Associate/Associate Professor

American Indians with Disabilities Community Needs Assessment Denver, Colorado (AIRRTC Project R-20)

Interviewer Job Description

Title Interviewer/American Indian Rehabilitation Research and Training Center

Examples of Duties and Responsibilities

- 1) Contacts all assigned interviewees (persons being interviewed) prior to interview, explains the purpose of the interview, and makes appointments for interviews.
- 2) Obtains signature on Informed Consent Form of person to be interviewed
- 3) Submits Interviewee Billing Statement to Libby Reeg for interviewee payment.
- 4) Checks completed questionnaires for clarity of recorded responses.
- 5) Keeps a record of all contacts, interviews completed, and mileage on Contact Log.
- 6) Mails completed questionnaires to supervisor (Catherine Marshall, Ph.D.) on schedule.
- 7) Informs supervisor immediately of any problems related to the project.
- 8) Submits Interviewer Billing Form to supervisor to receive payment.

Knowledge and Skills

- 1) Has knowledge of values and communication styles of the various American Indian tribes represented in Denver.
- 2) Can demonstrate making and keeping appointments and meeting deadlines.
- 3) Has some skill in written and verbal communication.

Minimum Qualifications

- 1) Has or can access reliable transportation.
- 2) Can attend 3-day training scheduled for January 9, 10, and 11, 1990 at the Denver Indian Center, Denver, Colorado.

Worksite

Denver, Colorado



Name	Phone	
Address	<u>Tribal Affiliation</u>	
	<u> </u>	

Interviewer Information

REG	REQUIRED			
1.	Will you be available to attend a three-day training session in Denver scheduled for January 9, 10, and 11, 1990?	םח	Yes No	
2.	Will you be available to conduct your first interview on January 12?	מם	Yes No	
3.	Do you have reliable transportation?	חם	Y es No	
4.	Can you be available to interview on evenings and weekends?	00	Yes No	
5.	Have you been employed (or done volunteer work) in human services or education?	00	Yes No	
6.	Have you ever conducted phone interviews?	aa	Yes No	
7.	Have you had jobs which required you to go into peoples' homes? If yes,	00	Yes No	
	census worker surveyor/interviewer sales person party coordinator (Avon, Tupperware, etc.) other (specify)			
8.	Will you feel comfortable going into a stranger's home to conduct the interview?	0 0	Yes No	
9.	Are you comfortable working independently, with limited super-taion?	a a	Yes No	
10.	Are you responsible about meeting deadlines?	a a	Yes No	
11.	What Native languages do you speak fluently? a) b) 1(5)			

-American Indian Rehabilitation Research and Training Center



December 15, 1989

Susan F. Davis 431 Alpine St. Longmont, CO 80501

Dear Ms. Davis:

I am delighted with your interest in working as an interviewer for our research project in Denver. The required interviewer training will be held in the Denver Indian Center Development Corporation building, 4450 Morrison Road (just across the street and a bit south of the Denver Indian Center). The training will begin at 9:00am on the 9th and 10th and at 8:00am on the 11th. All three days we will meet until 5:00pm.

Mr. Arlen Rhoads of the Denver Indian Center is handling the screening of applicants for me. He should be giving you a call soon. If you do not hear from him, give him a call at 936-2688. If you have any questions about this position, or find that you can not attend the training, please call me at (602)326-9064. If you do not receive an answer at this number, please leave a message for me at (602)523-4791.

I hope you are enjoying the holidays. I look forward to working with you in January.

Cordially,

Catherine A. Marshall, Ph.D.

Cathy Marshall

Research Associate/Associate Professor



Appendix H Interviewer Training Agenda





American Indians with Disabilities Community Needs Assessment

Interviewer Training

Denver Indian Center
Development Corporation
4450 Morrison Road
Denver, Colorado
January 9-11, 1990

Date/Time	Topic	Trainer(s)
January 9, 1990		
9:00 - 9:15	Introduction	Marilyn Johnson, Ph.D. Director, AIRRTC
9:15 - 9:30	Overview of Project	John Compton, Director Vision Quest and Associate Director, Denver Indian Center
9:30 - 9:45	Overview of Training	Catherine Marshall, Ph.D. Research Associate, AIRRTC
9:45 - 10·45	Disability Information	Barbara Bradford Associate Trainer, R & T Center on Independent Living
10:45 - 11:00	BREAK	
11:00 - 12:00	Disability Information	Barbara Bradford
12:00 - 1:00	LUNCH	
1:00 - 2:00	Services Information	Vera Mitchell, Director Community Health Services Denver Indian Health and Family Services
2:00 - 2:30	Rehabilitation Services	Jim Weiland, Coordinator for Native American Programs State of Colorado, Rehabilitation Services
2:30 - 2:45	BREAK	
2:45 - 3:15	Services Information (SI-1 to SI-11)	Catherine Marshall
3:15 - 4:30	Culturally Sensitive Interviewing Strategies	Margaret Tyon, Coordinator Serfor Citizens Denver Indian Center
4:00 - 5:00 ÖÖ	Questions and Answers	Catherine A. Marshall Marilyn J. Johnson
HOMEWORK	(1) Review Instrument (2) Read Training Manual	



January 10, 1939		
9:00 - 10:00	Interviewing Techniques: Lessons learned from Pilot Test!	Marie-Therese Archambault Denver Katert Circle/Catholic Church
10:00 - 10:15	Confidentiality	Marie-Therese Archambault
10:15 - 10:30	BREAK	
10:30 - 12:00	Review and Critique of Demonstration Video	Catherine Marshall Marie-Therese Archambault
12:00 - 1:00	LUNCH	
1:00 - 3:00	Questions Regarding Training Manual Review of Instrument and Consent Form	Catherine Marshall
3:00 - 3:15	BREAK	
3:15 - 5:00	Review of Record Keeping	Catherine Marshall
January 11, 1990		
8:00 - 10:00	Interviewer Practice in Dyads	Catherine Marshall Barbara Bardford Art Zamora, Psyonal Program and Training Specialist, Office of Rehabilitation Services, Department of Education - Region VIII
10:0C - 10:15	BREAK	
10:15 - 12:15	Interviewer Practice in Dyads	Catherine Marshall Barbara Bardford Art Zamora
12:15 - 1:15	LUNCH	
1:15 - 3:15	Establishment of Reliability	Catherine Marshall Marie-Therese Archambault Barbara Bradford
3:15 - 3:30	BREAK	



3:30 - 5:00

Constions and Answers Assignment of Interviewees

Appendix I

Correspondence Related to "Consumer Concerns"





American Indian Rehabilitation Research and Training Center



February 15, 1990

Dear

Thank you for helping us with our study regarding the needs of American Indians in Denver who have disabilities. We believe that for several people who were interviewed, there was some confusion regarding the attached items.

In order for us to use your answers in our study, please:

- 1. Read each of the 40 statements.
- 2. In the first column, circle the number which best describes how important the service is to you.
- 3. In the second column please rate your satisfaction or happiness with each of these items <u>based on conditions as they are now in Denver</u>.

The attached definitions may help you. Please return the statements immediately in the enclosed envelope.

Please call

if you have any questions.

Cordially,

Catherine A. Marshall, Ph.D.

Research Associate Professor

Marshall Marshall

cc:

ner.

	Please si	ign your	name	and	return	this	immediately	in	order	for
us to	use your	answers	in our	stuc	iy.		•			

I have read each of the statements (or they have been read t
me) and have rated my satisfaction (or happiness) with each
based on conditions as they are now in Denver.

Signature	Date
o.g	Date

Thank you for your help!



DEFINITIONS

Accessible Easily and independently entered or obtained.

Barriers can be furniture, narrow aisles, stairs,

lack of amplification, attitudes, etc.

Consumer A person who uses service agencies in the

community.

Disability A long-term (chronic) condition which may affect

one physically, emotionally, or intellectually.

Respite Care Assistance in caring for a person with a disability

while primary caregiver is, e.g., shopping,

working, on vecation, etc.



Appendix J

Correspondence to Recruit Interviewees Flyers Used to Recruit Interviewees





American Indian Rehabilitation Research and Training Center

December 12, 1989



Dear

Our study with American Indians who have disabilities is progressing; our survey instrument is currently being pilottested in Denver and we plan to begin interviews on January 12. The interviews will probably be conducted through mid-February. Please find enclosed:

- 1) A very brief fact sheet about our project entitled, "Explaining the Study."
- 2) Flyers advertising our study. Please distribute as you can; list your own name as a local contact person if you would like or just leave blank [I am also sending flyers to several other persons and agencies]. If you are able to enclose the flyer in your newsletter to parents, please let me know. I will be happy to provide the number of flyers that you need.
- 3) "Release of Information" forms. Please have anyone who is interested in being interviewed for this study complete one of the forms and mail to me as soon as possible. My address is:

1816 E. Waverly Tucson, AZ 85719

Thank you again for your interest in this project. I appreciate very much your willingness to help!

Cordially,

Catherine A. Marshall, Ph.D.

Carry Marshall

Research Associate/Associate Professor

Institute for Human Development ❖ Northern Arizona University P.O. Box 5630 ❖ Flagstaff, Arizona 86011-5630 ❖ (602) 523-4791

American Indians with Disabilities Community Needs Assessment

Denver, Colorado January 1990

Purpose

To understand the needs and concerns of American Indians in Denver who have

disabilities.

Procedure

You will be asked to participate in an interview that should take approximately

2 hours.

Voluntary

You may refuse to answer any questions

or stop the interview at any time.

Compensation

You will receive \$20.00 for completing

the interview.

Benefits

Improved service delivery to American Indians in Denver who have disabilities.

For more information, contact:

Catherine A. Marshall, Ph.D.
American Indian Rehabilitation
Research and Training Center
P. O. Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791

OR

Local Contact Person

Agency

Phone Number

WANTED

Disabled Native Americans (ages 14-79) \$20.00 PAID

WHY

To interview about services available to them in the Denver Metro area.

WHEN

Before February 9, 1990 (make contact)

WHO

Margaret Tyon-DIC 936-2688

Marie-Therese Archambault 480-9469



DISABLED NATIVE AMERICAN?

Are you . . . a friend or relative . . . ?



Appendix K

Interviewer Agreement For Services





American Indians with Disabilities Community Needs Assessment Denver, Colorado (AIRRTC Project R-20)

American Indian Rehabilitatic Research and Training Center Institute for Human Development Northern Arizona University

AGREEMENT FOR SERVICES

I,(pleasinterviews assigned to me. I understand that has not been assigned to me. I understand the completed and returned to my supervisorwiteme.	at all pilot-test interviews must be
I understand that payment for services American Indian Rehabilitation Research and \$25.00 for each interview completed homes of persons to be interviewed readings must be submitted), or to a both the interviewer and the person	ITraining Center is as follows: I, to include round trip travel to the (beginning and ending odometer in alternate location agreed upon by
Signature	 Date



Appendix L

Denver Indian Center Office Space Agreement



105





DENVER INDIAN CENTER, INC.

4407 MORRISON RD. . DENVER, COLORADO 80219

Administration 936-2688 / 937-0401

Adult Education 936-2688 / 936-2898

Circle of Learning 936-2688 / 936-2898

MEMORANDUM

Employment Training 937-0401

Human Services 936-2688 / 936-2898

Senior Citizens 936-2688

Vision Quest 937-1005

To: Wallace E. Coffey
Executive Director

From: John Compton JC

Re: Use of DICDC Office Space for Indians with Disabilities Project

Date: January 16, 1990

I have reserved the office near the pop machine in the back area of the DICDC Building for the use of the interviewers conducting the survey on the Indians with Disabilities Project for the American Indian Rehabilitation Research and Training Center (AIRRTC). They will use it to store non-confidential materials and to conduct interviews with Indian respondents who would rather come here instead of their homes to be interviewed. The Project should be concluded in March so they will need the space until then. Dr. Catherine Marshall indicated the room would be adequate for their needs.

Sister Marie-Therese Archambault is the person in charge of the interviewers in Denver representing the AIRRTC for this Project.

cc: Dr. Catherine Marshall Sister Marie Therese Archambault



Appendix M Interview Verification





R-20 Interview Certification

Name		
Phone#		
l. Was your interviewer courteous? Yes No		
2. Did the interview seem relevant to your concerns? Yes	No	
3. Do you plan to attend the public meeting scheduled for April 17?	Yes	No
4. Do you have any questions about this project?	Yes	МО



QUALITY ASSURANCE

Fieldwork Verification

Approximately 10% of all completed interviews (selected randomly) will undergo a verification process. The purpose of this procedure is to: 1) verify that the interview was actually completed, 2) measure the accuracy of recorded responses, thereby insuring the quality of the data, and 3) inquire about any concerns the interviewee may have. Random interviewees will be re-contacted by the field coordinator or project secretary and asked a few brief questions which will satisfy verification requirements. Interviews which prove to be fraudulent (i.e., not actually administered) will result in the immediate termination of the interviewer responsible for the action. A random check of unsuccessful contacts will also be completed as possible.



Appendix N Agenda for Public Meeting





American Indians with Disabilities

Denver Indian Center 4407 Morrison Road Denver, Colorado

Public Meeting April 17, 1990 6:00 p.m.

Moderator Sr. Marie-Therese Archambault, OSF

Welcome Wallace Coffey, Executive Director

Denver Indian Center, Inc.

Overview of Project Dr. Marilyn Johnson, Director

American Indian Rehabilitation Research

and Training Center

Experiences of luterviewers

Susan Davis

Summary of Results Dr. Marilyn Johnson

Consumer Concerns Barbara Bradford, Associate Trainer

The Research and Training Center on

Independent Living University of Kansas

"Open Mike" Concerned community members, program directors,

services providers. All are encouraged to comment on the results of the study and to make recommendations for community services which will better meet the needs of American Indians with disabilities in the

Denver area.

Research conducted by
Northern Arlzona University
American Indian Rehabilitation
Research and Training Center
Institute for Hurnan Development
P. O. Box 5630
Flagstaff, AZ 86011
(602) 523-4791





Appendix O

Correspondence with Interviewers Regarding Input for Public Meeting





-American Indian Rehabilitation Research and Training Center



February 23, 1990

Dear

Please find enclosed a <u>Project Evaluation Form</u> which I am asking everyone who participated with us as interviewers to complete (Yes, that's right, more paperwork!!). Please return it to me by March 9, or take it to the planning meeting which Sister Marie-Therese is having, also on March 9. A stamped envelop is provided for your convenience.

Sister trie-Thorose asked me to remind you that her March 9 meeting will be held at the Vision Quest building (4450 Morrison Road) at 6:00 pm; please bring a potluck dish to share for dinner. We will very much appreciate your input at that time as to how you believe the public meeting should be structured, and the should be invited to attend (in addition to the general public).

It will be sending you flyers announcing the public meeting in the next week or so. For now, mark April 17 on your calender. We are having a reception for the interviewers at 5:00; the public meeting will begin at 6:00 pm.

The enclosed information regarding the internship and student support may be of interest to you. I am looking forward to seeing you at the reception. Please plan to join us!!

Cordially,

Cathy Markall

Catherine A. Marshall, Ph.D. Research Associate/Associate Professor

pc: Sister Marie-Therese Archambault



Appendix P

Correspondence and Publicity Related to Public Meeting





American Indians with Disabilities

Results of a recent survey conducted by the Northern Arizona University American Indian Rehabilitation Research and Training Center will be presented at the

Denver Indian Center

4407 Morrison Road Denver, Colorado



April 17, 1990 6:00 p.m.

Interviewers

Sr. Marie-Therese Archambault, OSF Coordinator

Michael Aragon Cecil R. Campbell Susan F. Davis Evelyn L. Finley

Shirley Gray Eagle Virginia Grimm Paul J. Hanway Lila Medicine-Kenny



Jim Weiland

Colorado Rehabilitation
Services
131 866-2866

Margaret Tyon

Denver Indian Center 936-2688

Vera Mitchell

Denver Indian Health and Family Services 320-8668



Results of disabled Indian survey bleak

By Robert Jackson

Rocky Mountain News Staff Writer

A survey of 100 disabled American Indians in the Denver area found only 25 who are employed, and only 19 who have yearly incomes of more than \$10,000, say two Arizona researchers who conducted it.

Marilyn Johnson and Catherine Marshail, of the American Indian Rehabilitation Research and Training Center at Northern Arizona University in Flagstaff, will discuss the results of the survey tonight at 6 p.m. at the Denver Indian Center, 4407 Morrison Road.

They're encouraging Indians with disabilities to attend to learn what medical resources are available to them. and provide recommendations for community services which will better meet their needs. said Johnson.

The survey was conducted in association with the Colorado Rehabilitation Services. the Denver Indian Center and Denver Indian Health and Family Services.

"We do recognize there are many needs of American Indians with disabilities," said Johnson. "But many of them are not aware of the resources available to them. We want to make these resources known to them. You can't ask

Run, films, lectures highlight Indian heritage week

FORT COLLINS — Colorado State University will celebrate its 10th annual Native American Heritage Week with a series of lectures.

films and concerts April 22-28.

The celebration begins at 9 a.m. Sunday with a 5K "Too Long Run" on the Colorado State Oval. The run, now in its second year, got its name last year when when a student inaccurately measured the course. The mismeasurement made the course noticeably longer than five kilometers. The course will be the correct length this year, but the name will remain.

Other events of the week:

- The film Broken Rainbow will be shown at 7 and 9:30 p.m. Friday in the Lory Student Center (LSC). This examination of the relocation of traditional Navajo people from their homes in Big Mountain, Artz., won the Acaderrry Award for best documentary in 1985.
- The film I'd Rather Be Powwowing will play at noon Monday, Room 206, LSC. This film, produced entirely by American Indians for public television, presents a portrait of contemporary Indian values.
- British Columbian author Lee Maracle, of the Cree and Salish tribes, will discuss writing and whether Europeans can write in a native voice, 7 p.m. Monday, Room 224, LSC.

- Showing of the film Harold of Orange, which depicts the relationship between reservation communities and bureaucracies, noon, April 24, Room 206, LSC.
- A lecture on how to bridge American Indian tradition with modern American living, led by Wallace Coffey, director of the Denver Indian Center, 6:45 p.m. April 24, in Room 228, LSC.
- Concert by R. Carlos Nakai, an artisan, lecturer and performing artist who specializes in indigenous North American culture and music; 7 p.m., April 25, Sculpture Garden, LSC.
- A lecture, "Coyote and the Outer World," by Nakai, 10 a.m., April 26, Room 222, LSC.
- Screening of the film John Kim Bell, noon, April 27, Room 164B, LSC. This film tells the story of Bell, the first American Indian symphony conductor.
- Minimal lecture by Frank Dukepoo, a geneticist with Northern Arizona University at Flagstaff, 6 p.m., April 27, Room 202, LSC.
- Screening of the film Powwow Highway, 7 and 9 p.m., April 27, LSC Theater.

Native American Heritage Week is sponsored by the Native American Student Association and the American Indian Science and Engineering Society, with assistance from Native American Student Services.

for help if you don't know it's available."

Johnson said the survey of 55 women and 45 men, ages 14 to 70, is unique, so there's nothing to compare the results to.

Of those interviewed, 57 had yearly incomes of less . to share with us what ways than \$4,499, and 81 had year. they perceive as best to trely incomes of less than spond to their disabilities," **\$**10,000.

"We want them to be able Johnson said.



-American Indian Rehabilitation Research and Training Center



April 3, 1990

Mr. James Dixon
Regional Commissioner
Department of Education
Rehabilitation Services Administration
398 Federal Office Building
1961 Stout Street
Denver, CO 80294

Dear Mr. Dixon:

The American Indian Rehabilitation Research and Training Center has recently completed a survey regarding the needs of American Indians with disabilities who live in the greater Denver metro area. Approximately 100 face-to-face interviews with consumers have been completed in the past two months. The survey was conducted in association with the Colorado Rehabilitation Services, the Denver Indian Center, and the Denver Indian Health and Family Services.

A Public meeting is scheduled for 6:00 p.m. April 17 at the Denver Indian Center, 4407 Morrison Road. The purpose of the meeting is to share preliminary results of the study with the Indian community and to obtain recommendations from consumers for improved service delivery.

I am inviting you to attend this meeting. I have enclosed a copy of the tentative agenda. The agenda has been developed in collaboration with Sister Marie-Therese, our on-site coordinator for the project, and the project interviewers. If you cannot attend the meeting, a copy of our final report, will be available to you upon request.

Sincerely,

Marilyn J. Johnson, Ph.D. Director

Appendix Q

Service Providers Attending Public Meeting





Sister Marie-Therese Archambault 2626 Osceola Street, #1409 Denver, CO 80212 (303) 480-9469

Mary G. Baca 4581 West Virginia Avenue Denver, CO 80219 (Youth Statistics)

Debbie Blackketter
Office for Civil Rights
Department of Health and Human Services
1961 Stout Street, #1185
Denver, CO 80294-3538
(303) 844-2024

David Box Colorado Department of Labor and Employment 1070 Bannock Denver, CO 80204 (303) 620-4627

Susan F. Davis 431 Alpine Street Longmont, CO 80501

William U. Farrell
Technical Assistanct Coordinator
U.S. Department of Education
Office for Civil Rights-Region VIII
1961 Stout Street
Denver, CO 80294

Vincent A. Hayes Social Security Administration Department of Health and Human Services 1845 Sherman Street Denver, CO 80203 (303) 866-1155

Laura Hershey, Director Commission for Persons with Disabilities 303 W. Colfax, #825 Denver, CO 80204 (303) 640-3056

Larry Holt
Social Security Administration
Department of Health and Human Services
1845 Sherman Street
Denver, CO 80203
(303) 866-1155

Vada Kyle-Holmes, Regional Manager Office for Civil Rights Department of Health and Human Services 1961 Stout Street, #1185 Denver, CO 80294-3538 (303) 844-2024

Joe Lewis Vocational Counselor EmployAbility, Inc. 789 Sherman, Suite 520 Denver, CO 80203 (303) 861-0116 (Voice) (303) 861-2735 (TTY)

Rick Parmelee
Executive Director
Resource Center for the Disabled
Amoco Building
P. O. Box 800
Denver, CO 80201
(303) 830-4965

Gail Redhorse, RN-BSN Mental Health Corporation 75 Meade Street Denver, CO 80219

Rockling Todea
Denver Indian Health and Family Services
1739 Vine Street
Denver, CO 80206

Margaret Tyon
Denver Indian Center
4407 Morrison Road
Denver, CO 80219

James T. Weiland Rehabilitation Services State of Colorado 15.75 Sherman Street, 4th Floor Denver, CO 80203-1714 (303) 866-2866

Suzanne M. Wiggins Program Manager Mile High United Way 2505 18th Street Denver, CO 80211-3907 (303 433-8383, ext. 228



Appendix R

"Consumer Concerns" in Order of Average Satisfaction





American Indian Rehabilitation Research and Training Center Consumer Concerns Report Denver, Colorado

April 17, 1990

Concerns Report Survey Results in Order of Average Satisfaction

item#	Survey Question	Average Satisfaction	Average Importance	• Don't know	n per item
16	Local media provide education and adequate information for American Indians who have disabilities.	29%	87%	28	66
12	Social agencies have outreach services to contact all American Indians in the community who have a disability.	31%	93%	24	71
19	Advocates network to gain community support for issues related to American Indians with disabilities.	33%	90%	27	68
20	You know your rights (regarding e.g., housing, employment, social services) as a disabled citizen.	34%	94%	23	70
15	Social agencies inform you about <u>legal issues</u> related to disability and independent living services.	34%	85%	33	64
-	Social agencies inform you of benefits and services for which you qualify.	35%	93%	9	86

^{*} Satisfaction rating - "I do not know if this service is available."



hec	Survey Question	Average Satisfaction	Average Importance	* Don't know	n per item
27	Door-to-door transportation services are adequate and available any time of the day or night.	37%	83%	42	55
4	Affordable housing (both private and public) is accessible to all types of disabled residents.	38%	86%	18	79
13	Examinations to assure the proper fit of an assistive device (e.g., wheelchairs, braces, hearing aids, glasses) are available at an affordable price.	41%	92%	19	78
10	Social agency staff treat you with dignity and respect given your cultural background.	42%	92%	7	90
14	Assistive devices (e.g., wheel-chairs, orthopedic appliances, phone amplifiers, hearing aids, seeing eye dogs) are available at an affordable price.	42 %	84%	35	58
26	Affordable transportation services are available as needed for people with disabilities.	43%	90%	19	78
17	Adequate vocational training is available and accessible to you.	43%	87%	34	63

^{*} Satisfaction rating - "I do not know if this service is available."



ltem	Survey Question	Average Satisfaction	Average Importance	* Don't know	n per item
22	Doctors, nurses, etc., have enough knowledge of disabilities to provide safe and competent health care to American Indians who have disabilities.	44%	92%	9	85
18	Your vocational rehabilita- tion counselor gives you enough information to make good decisions.	45%	79%	38	55
8	Help (like advocates or legal assistance) is available for solving problems with landlords, employers, utility companies, etc.	46%	85%	19	76
5	Disabled homeowners can get financial assistance to remodel their homes in order to increase accessibility, safety, and fuel efficiency.	47%	33%	30	67
9	Assistance with housekeep- ing is available.	48%	74%	29	64
29	It is possible to travel within the community in a safe and convenient manner.	49%	92%	12	85
40	Financial assistance is available to students with disabilities who want to attend college or technical school.	49%	90%	36	60
23	Health care providers treat you with dignity and respect.	50%	90%	4	92

^{*} Satisfaction rating - "I do not know if this service is available."



Item	Survey Question	Average Satisfaction	Average hr.portance	* Don't know	n per item
28	Streets and sidewalks built in areas of public housing facilitate safety and access for people with disabilities.	52%	90%	14	81
36	Churches are sensitive to the needs of members with disabilities.	52%	85%	16	81
3	Landlords will make moderate changes to make their rental units safe and barrier-free.	53%	85%	17	79
30	Public transit systems (e.g., buses, cabs) are safe and accessible.	54%	87%	18	79
35	Churches are barrier-free.	54%	87%	13	83
21	You can successfully obtain services for your needs on your own.	56%	87%	14	85
2	You can get respite care or attendant care <u>from an</u> agency for a disabled family member.	56%	81%	36	61
7	Landlords respect tenants' privacy, culture, and property.	58%	93%	4	93
24	Knowledge about proper nutrition is available.	58%	85%	10	83
32	Access to traditional religious services (e.g., sweat lodge) is available.	58%	78%	24	73

^{*} Satisfaction rating - "I do not know if this service is available."



Item	Survey Question	Average Satisfaction	Average Importance	* Don't know	n per item
37	Opportunities for adults to learn reading and writing are available.	59%	89%	24	72
39	Adequate educational opportunities are available for you.	59%	89%	30	66
25	Practice of proper nutrition, (e.g., with people who have diabetes) is stressed.	60%	90%	9	86
38	Special services in your schools provide good assistance for students with disabilities.	60%	88%	34	62
1	Support and assistance are available from family, friends, and neighbors to care for a disabled family member.	62%	87%	11	85
6	The physical design of the place you live allows you to be independent.	62%	87%	14	83
31	Accessible parking spaces (i.e., handicapped parking) are available and adequate.	63%	88%	6	90
34	Access to other (e.g., Christian) religious services is available.	63%	79%	15	82
33	Access to the Native American Church is available.	64%	74%	31	64
'	•	ı	· •	l	

^{*} Satisfaction rating - "I do not know if this service is available."



Appendix S Interviewer Project Evaluation





American Indians with Disabilities Denver, Colorado

Project Evaluation Form

ī.	Did the training pr manner (please cir	repare you to	conduct the inter	rviews in an effective
	Strongly Agree l	Agree 2	Disagree 3	Strongly Disagree 4
2.	In what ways could been improved?	the training	g you received as a	an interviewer have
3.	Are there any items added to the inter removing or addin	view instrum	believe could be re ent? Please give y	emoved from or your reasons for
		Adde	d Items	
Interv	riew Instrument Items		Reasons	· · · · · · · · · · · · · · · · · · ·
		Remov	red Items	
Interv	riew Instrument Items		Reasons	
				V-1-



If we obetter	io this research in another city, what might we do differe locate American Indians who have disabilities?
meetin	specific issues would you like to see brought out at the pul ig? Which items on the interview instrument would you in hear presented?
conun	ollow-up activities might be conducted during the next yeue the process of improving services to persons with disa Denver area?



PROJECT R20 - PROJECT EVALUATION DONE BY INTERVIEWERS

		1: QUESTION	# 1	
Bar:	Element:	Count:	Percent:	
1	STRONGLY AGREE	5	71.429	-Mode
2	AGREE	1	14.286	
3	DISAGREE	1	14.286	
4	STRONGLY DISAGREE	Ξ 0	0	

ERIC Full Text Provided by ERIC

AIRRTC

PROJECT R20 PROJECT EVALUATION DONE BY INTERVIEWERS (n=7)

QUESTION #2:

In what ways could the training you received as an interviewer have been improved?

The length of training sessions seemed long and drawn-out. Perhaps, shortening a three day training session to two days would suffice.

More information on resources in the Denver Metro area may have helped immensely. Maybe a referral or list of resources from United Way.

Maybe a bigger place, more private. The done interviews before and from what we learned and seen, it was a terrific training session.

I think you have covered everything and I was very satisfied. I had no problem with clients.

These questions should be brief and to the point. Clients lose interest when you drone on and on reading to them.

More time, especially in observing the interview actually being conducted. Also, the instrument has too many questions. I think the instrument could be more effective if properly streamlined.

QUESTION # 3:

Are there any items which you believe could be <u>removed from</u> or <u>added to</u> the interview instrument? Give reasons.

ADDED ITEMS

<u>Item</u>	Reasons
Blanks in the SI Section, Column E	Could help the format of survey as some interviewers had two #7 "other" responses.
	Everything seems to be OK and very reasonable.
Better explanation or deletion of vocabulary	People had trouble understanding some concepts/questions due to terminology.



ITEMS TO BE REVISED

Item

Consumer section

"Caretaker" section

Indian Medicine ways

Revise the interviewee evaluation

Perhaps it [the instrument] should be revised with a less educated Indian person as a "text-reader". In general, we found the Indian population to be less verbal and more relationship/experience oriented.

Reasons

Too long and "wordy". It doesn't work very well with most Indians.

Rework it to make the change-over spots less awkward.

Be more specific about which medicine ways; eg. sage, sweat lodge, medicine way etc.

So that it reads more clearly at the end and simply.

REMOVED ITEMS

Item

CC-21

There seemed to be some overlap with questions while other questions continue to be too wordy.

Consumer Concerns

Native Medicine Way

Native Medicine Way

CC-11 and CC-12

Disability Information (o) Having a sexual relationship

Page 21. SO-7 a-i

Pages 14-18 (Consumer Concerns)

Everything seems to be OK and very reasonable.

Reasons

Parties have no satisfaction reply if they can find for themselves; they would have to be satisfied.

The interviewees became bored after the first 10.

Interviewees asked "Do we have to talk about this?"

The name itself seems so personal! Change to: "Do you use the following for anything: roots, sage, sweetgrass, Indian tea?"

No social agency treats you with respect anytime. They give a person the impression they are paying out of their own pockets. I am yet to have an agency inform a handicapped person of any benefits.

No Native American would discuss that. Interviewees were uneasy speaking of this.

I really don't think it is important.

Should be condensed.



QUESTION #4:

What additional supports or help would you have liked to have had while conducting interviews?

How to keep interviewees on track. Often, they tended to story-tell between responses. And to have a follow-up team, of sorts, check on these people. I often felt helpless.

None. With the pilot study, Dr. Marshall was always a phone call away.

More information on resources in the Denver Metro area may have helped immensely. Maybe a referral or list of resources from United Way.

Maybe have the money ready so the interviewers can pay them on the spot.

None.

None.

More interaction with other interviewers. If the interviewers could have met during the time allotted, this would have made for better communications.

QUESTION # 5:

If we do this research in another city, what might we do differently to better locate American Indians who have disabilities?

A team of investigators to go to various service delivery agencies to identify clients. More publicity via radio, TV, and print.

Contact Indian agencies or centers within the city and ask for names, addresses. I never got a single name from the Center Health Board; I went on my own.

Put ad in paper 2 weeks in advance.

More time for advertising, more of a wider scope of the vicinities, more time for the interviewers. Maybe a longer training period. Time schedules for interviewers(?)

Have the interviews scheduled in advance by outreach workers familiar to the interviewees with disabilities.

Do a greater preparation so that there are interviewees ready at the onset of interviewing.

I do feel that the working with the Indian agencies greatly assisted in the search. Perhaps, an ad in the local newspaper could have been tried also.

QUESTION #6

What specific issues would you like to see brought out at the public meeting? Which items on the interview instrument would you most like to hear presented?

The statistical break-down of disabilities per category i.e. diabetes, arthritis, heart problems etc. Also, an announcement of a listing of the services within and outside the Indian community that address the needs that were most frequently listed.



A place for the interviewers to give a report of their experiences and which issues they noted overall. Especially, regarding coordination of services.

The lack of resources the interviewees need. The lack of concern by outreach workers, homehealth aids etc have for the elderly with disabilities.

Just more information on all disabilities, medical issues, hospital issues; more "how to," where, and what resources are available at an affordable price.

People not keeping their appointment.

Have referrals set up for psychiatric care, dental care, and where to get these services. If a person goes to the health board, dental work is a one time service and work is not quality work.

How to direct people to service delivery agencies to access services to address their disability(ies).

QUESTION # 7:

What follow-up activities might be conducted during the next year to continue the process of improving services to persons with disabilities in the Denver area?

Interviewers' meeting. More community involvement. A meeting with business and service delivery agencies to address consumer concerns.

Do the same clients and see the results.

Don't really understand the question all that well. But, almost all of the people I interviewed needed dental and medication the most.

Meetings with different policymakers. Meetings with several types of dignitaries for Indian people in the Denver Metro Area. What types of programs available and what types of program willing to work with the American Indians in the Denver Metro Areas.

Follow-up on the Indian Center to see that they are implementing a program or suggest the hiring of Native American outreach workers.

If there are to be follow-up activities, a full-time reliable person in a paid position will have to do it. The existing services have not and probably will not be able to continue this process of improving services to Native Americans with disabilities.

All in all an admirable project and very worthwhile.

I do feel that clients/ consumers of the agencies which are frequented/patronized should have an opportunity to voice their approval and disapprovals of the service. Perhaps a quick and direct evaluation slip could be offered.



Appendix T

Outreach to Minorities with Developmental Disabilities



134





4126 South Knox Court Denver, Colorado 80236 (303) 761-0220, Ext. 332

OUTREACH TO MINORITIES WITH DEVELOPMENTAL DISABILITIES

Background

The Colorado Developmental Disabilities Council has been approached by representatives of Denver Minority Organizations to target in on service needs of individuals who are minorities with developmental disabilities.

In March, 1981 the Council established a Committee for Concerns of Minorities with Developmental Disabilities." The Committee was charged with presenting a program at the June, 1981 planning retreat of the Council and in establishing goals and objectives for FY '82.

At the June Planning Retreat, consumer and professional representatives of Black, Spanish and Native American organizations presented the major barriers which they had identified to getting services for minority persons with developmental disabilities.

In identifying objectives for the Council, the following were assigned to the Committee for Concerns of Minorities with Developmental Disabilities.

- 1. Develop an outreach project.
- 2. Collect information on the availability of services to minorities with developmental disabilities.
- 3. Act in a monitoring capacity for all Council activities to assure inclusion of issues related to minorities.
- 4. Participate in the grant selection process of the Council by reviewing proposals and affirmative action data and plans.

The proposal which follows will address objectives #1 and #2 above.

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Statement of Need

The 1980 census indicates that approximately 23% of Colorado's population is of Spanish, Black, American Indian/Eskimo/Aleut, Asian/Pacific Islander or other Non White origin.

Utilizing the 1% prevalence rate for developmental disabilities, approximately 6,578 individuals in Colorado are minorities with developmental disabilities. Adding to this figure the number of individuals who would be considered disabled but are not necessarily developmentally disabled would undoubtedly show an even larger percentage of individuals in Colorado whose special needs may be compounded by the unique cultural barriers which they may experience in getting services.

Outreach to Minorities with Developmental Disabilities Fage Two

Among the barriers which have been identified to date are:

- language

- lack of concern by general public.

- lack of professionals in system who can empathize with unique cultural differences.

- attempts to access services have yielded negative results in the past.

- fear of losing custody of children by identifying oneself to the "system".

- minorities not knowing what their rights are.

Goals of Outreach Project

- 1. To provide information and referral to minority consumers about services and entitlements available to meet their needs or the needs of their disabled family member.
- 2. To provide follow up to consumers identified to determine whether they have accessed the services and to ascertain any barriers encountered in doing so.
- 3. To obtain data on individuals not receiving services or being underserved so that agency planning may be impacted for the following year.
- 4.: To determine to the extent possible how information collected correlates with information being collected by other Information & Referral and Outreach efforts in Denver, i.e., ARC-Colorado, Denver ARC.
- 5. To provide information to agencies impacted regarding the services needs of the specific minority populations in their area.

Project Design

The Project will be based at the Department of Social Services, Division of Rehabilitation. The Division of Rehabilitation is a centrally located state agency with offices throughout the state. The Division has an already existing network which reaches disabled and developmentally disabled individuals. A federally funded project known as the <u>Client'Assistance Project is in place at State Rehabilitation which can assist individuals in identifying services.</u>

Rehabilitation has limited resources to target into specific populations and this project will help to strengthen the efforts of Rehabilitation to provide additional services to individuals in need in Colorado.

Personnel

Three and three/fifths positions will be created to be co-located in the following agencies:

1 FTE Urban League of Metro Denver

1 FTE LaRasa

1 FTE Tiyospaye Crisis Center

3/5 FTE San Luis Valley Center for Handicapped (pending)

Each position will have a working title of Community Liaison.



Personnel will be recruited and hired through State Personnel.

April 7, 1983

To:

David Gies, Program Administrator

82-020

From:

Tiyospaye Crisis Center

Subject:

Program Report For Months Of January 1983 Through March 1983

CONTACT SHEETS

See attachments.

MEETINGS/WORKSHOPS ATTENDED

Fitzsimmons Hospital (Nurses Outreach Workers)
Inter-tribal Heritage Project and Horse Riding Stable
Senior Citizens - Meals On Wheels - DNAU
Family Builders By Adoption
Colorado Epilepsey Association
ArtReach

RECEIVED

APR 13 1983

Division of Rehabilitation Grants Management Section

The meeting with the hospital personnel and outreach workers (approximately 150) was to introduce our work with the handicapped, and to see if we can assist them. We are on call to go to the hospital to provide support to patients who are transferred from the reservations. The idea of having a community worker (Native American) was introduced and will be further discussed.

The community outreach worker has been very active in volunteering time towards recruitment of handicapped persons to participate in a horse-back riding program. He has also introduced the Inter-Tribal Heritage Program to the riding stable, and they have been able to set up a summer program for the Native American youth.

The community outreach worker was seated on a panel for a 2 day workshop for the Family Builders By Adoption. Their purpose was to develop a training curriculum for the placement of handicapped children, also to discuss cultural and traditional awarenesses.

A few job sites were identified and referrals made to DNAU, Career Service (Manpower), NAUTP, Inter-Tribal Heritage Program and the Summer Youth Employment Program.

Spiritual ceremonies are continuing being held every other week and there is a very good participation by several clients.

IDENTIFY FOUR CASE LOADS

Case #1

This client was not referred by any one agency. His son was referred to this project by NAUTP. When the initial visit was made, the son was interviewed, and is considered legally blind, the worker was then told about father who was also blind. Starting to go blind at age 5, by 15 years old he had totally lost sight.

ERIC

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Client had relocated to Denver in June 1982 with his sons.

December 9, 1982

RECEIVED .

David L. Gies, Program Administrator

DEC 13 1982

Tiyospaye Crisis Center FROM:

Division of Rehabilitation

SUBJECT: Progress Report for months of July 1982 to November Section

Contact Sheets

See attached

Meetings/workshops attended

American Indian Higher Education Consortium

Native American Urban Transition Program

Denver Indian Health Board

Denver Native Americans United

- Senior Citizens Meals
- Senior Citizens Sewing Group
- Social Services
- Indian Child Care
- Career Service Center (Manpower)

Inter-tribal Heritage Project

Indian Education Program - Title IV - Denver Public Schools

HAIL - Holistic Approach to Independent Living

Atlantis Community

VA Hospital Fitzsimmons

ARC - Association for Retarded Citizens

Christian Indian Center

Representative from City Managers office, Oklahoma City

Justice Information Center

Family Builders by Adoption (Home Builders)

Colorado Epilipsy Association

Metro State - Disabled Student Assistance Center

Commission on The Disabled



Meetings/workshops attended (cont.)

GEMS - Growing Experientially Multi-displimary Service Special Education Administration - Denver Public Schools Horseback Riding Program for Disabled

The project continues to make referrals to resource agencies regarding available services to the handicapped including: food, clothing, housing, wheelchair repairs, parking permits, dental, testing for learning disabilities, auto repair, transportation, employment, hearings aides, etc.

Objectives

The project continues to meet and develop the goal and Objectives. Our areas of concern regarding education of client and agencies continues in the development of services available to client and also client and agencies expectation.

Problem Areas

The project continues to have problems in a number of areas but we feel that these problems are not major, and that time and energy can overcome them. Some of the areas are included from the first report and all do not see any change. These areas may be related to culture and tradition and have a tendency to be very difficult in making change. The projects concerns are as follows:

1. Because of the involvement of alcoholism the handicapped or disabled pers . is denied services or agencies. No services available to deal with the problem of alcohol and drugs amongst these individuals.



Problems Areas (cont.)

- 2. Not sensitive to handicapped or disabled persons use or request for a medicine man or services of the medicine man
- 3. Transportation is not available for handicapped or disabled persons to get to and from meal sites, service agencies, hospitals, social activities. Also included lack of transportation for those who would like to participate in Sweat Lodge ceremonies near Boulder.
- 4. Transition from reservation to urban setting creates culture shock, sterotyping and fear of social service agencies.
 - 5. Handicapped or disabled persons inability to pay for services that are available.
 - 6. Resource list available should be updated because it is used constantly.
 - 7. We feel a real need for more publicity in the community i.e. community newspapers, radio, T.V. etc.
 - 8. The lack of emergency housing for the handicapped is a continuous problem even though resource lists are available to the project. The occupation and waiting lists are extensive.
 - 9. Client developes a sense of dependency on worker, how do you let go. Also the fact that other family members not handicapped tend to have this dependency and therefore a need to get services.
 - 10. The initial interview is not enough time to develop the needed information because the client tends to be shy, does not like all the paperwork that is needed to get services.



Problem Areas (cont.)

- Too much identification is required by agencies for clients 11. to acquire services such as individual rent receipts when the extended family situation is practiced amongst the Native Americans.
- A misconseption on the part of the Native American as to 12. the living situation in the urban area in their transition from the reservation i.e. housing codes, utility payments, medical services, and public transportation.

Progress

- Education of services available for Indian handicapped and disabled persons including the service agencies.
- 95% of contacts made did not know services available. 2.
- Majority of agencies are very helpful and expressed concern 3.6 for the Indian handicapped or disabled persons. Also offered to assist in one way or other.
- Contact made with a medicine man who will assist by performing ceremonies on weekend and/or talking with handicapped or disabled persons if desired. Also transportation has been provided for several individuals who wished to participate in the Sweat Lodge ceremonies.
- In the process of establishing a food bank for the Indian , 5. community including handicapped and disabled persons in the metro area.
- Publicity of the project has been greatly advertised the 6. through word of mouth in the Indian community and also

Progress (cont.)

publicity done in The Handicapped Coloradan has been very valuable.

- 7. The ability to speak the Indian language or the fact that the community worker is Indian made the handicapped or disabled person feel at ease and more open about their problems.
- 8. Developed a follow-up sheet for follow-up and progress notes.

 (see attached)
- 9. Improvement of communication with other Indian agencies during the past few months due to reorganization of these agencies.
- 10. Purchased business cards for community worker and also made available business cards for volunteers. (see attached)
- 11. The community worker was able to assist several service agencies in providing information on Native Americans insights on Tradition and Culture, this helped to broaden their perspectives and ideas on who Native Americans are.
- 12. Award received from the U.S. Department of Health and
 Human Services. Article also submitted to The <u>Handicapped</u>
 Coloradan regarding this award.
- 13. The project has had a number of walk-ins just to see what we have to offer. These individuals are handicapped and non-handicapped.



TIYOSPAYE Crisis Center

4031 Osage Street Denver Colo. 80211 (303) 477-2567

December 9.

1982

RECEIVED

DEC 13 1982

Division of Rehabilitation

Grants Management Section

Ralph Ware · Chairman

Walter Littlemcon • Vice President • Exec Director

Muriel Ashmore • Treasurer

Carol Chargingthunder • Secretary

David Gies, Program Administrator Dept. of Social Services Division of Rehabilitation 1575 Sherman St. Denver, Colo

Dear Mr. Gies,

We as an agency serving our Native American people feel that the project has made an impact in the community, but feel that there is a lot more work to be done.

There are some issues that we wish to address in the future future meaning soon as at the end of the funding year. These issues are as follows:

- 1. A workshop to develop an awareness and education of the problems related to culture and tradition within the Native American, Chicano and black people, for those in funding positions.
- 2. A serious look at the intake forms that are being utilized and are the questions fitting the needs of each minority culture represented.
- 3. The development of public awareness through the media to further contacting clients.
- 4. We are considering traveling to New Mexico to visit the project located there that serves Native Americans. We hope to do this during the month of January 1983.

Tiyospaye Crisis Center is a non-profit organization

page 2

We stated in the past that we were going to try to limit paper work, I understand that at times that this difficult but — it seems as though we as a project are headed that way. I hope sincerely that the service provided to the Native American people will not be pushed aside for paper work.

Also our working relationship with Mr. Ingo Antonitsch, Director of the Commission on the Disabled, has been very satisfactory. He has provided a vast amount of resources and information regarding the handicapped community. We appreciate the opportunity to work with him.

I believe all our forms are submitted and up to date at this time. Thank you for your cooperation and consideration.

Sincerely,

Muriel Ashmore

Chairperson

Tiyospaye Crisis Center

MA/cct

December 3,1982

To: David Gies, Program Administrator

From: Tiyospaye Crisis Center

Subject: Report for the month of December, 1982

INTAKE SHEETS (December)

Previously Submitted

82-020

RECEIVED

APR 1 3 1983

Division of Rehabilitation Grants Management Section

MEETINGS ATTENDED

In-Service training (Marilyn Webb)
Regular Staff Meetings
Metropolitan State College - Disability Program
GEMS

GOALS AND OBJECTIVES

The project continues to meet and develop the goals and objectives. Our areas of concern regarding education of client and agencies continues in the development of services available to client and also client and agencies expectations.

PROBLEM AREAS

There are no visable! changes in the areas of problems of concern since the last report was submitted.

PROGRESS

- 1. A form was adopted to control the variou types of phone calls recieved and services requested.
- 2. A weekly report is also submitted to Mr. Ingo Antonitch the Director of the Commission on the Disabled, on services and activities orivided to be included in the Mayor's weekly report.

Progress continues to be made in all areas submitted in the last report.



L.

Appendix U Critiques of Final Report





i had eagerly awaited the arrival of your final draft assessing the needs of the Native American disabled in the Denver-metro area. Thank you for allowing me the opportunity to review the draft of the Final Report. After reading it, I found myself complacently setting it aside and feeling pleased to have been a part of the study. The report did not present any disagreeable information for me. In fact, your research package truly seemed to be the result of a community effort superbly coordinated by your tireless commitment to the project.

I particularly enjoyed the manner that you have presented the findings to include the history of Native American migration to urban areas, the demographics of the Colorado Indian population, the hypotheses for conducting such a study, the chronology of the project, the results, a review of the project's limitations, and an appendix of the correspondence and paperwork used during the project's development.

There were a lot of nice details included in the report. There were many recommendations offered by various people at various times in the study which were weaved throughout. The detail of the project's chronology was well-written. For example, I had completely forgotten about our informational booth at the March Pow Wow. The graphs, charts, and tables provided some powerful visual analyses of the results. Regarding a more critical view of the report would be better left to those academics within the university.

What is evident within this draft of the Final Report is the amount of work that went into the connecting of a university study with an already apprehensive American Indian community. I believe the process was a collaborative success. The study will provide valuable antecedent data which will remain significant for subsequent research to build upon. More importantly is the information that this report yields for service providers, agencies, and concerned Denverites. I'm encouraged by the possibilities for service delivery improvement as a result of this data.

It's been a pleasure to have been associated with this project from beginning to end. . . .

--Anthony Michael Aragon, M.A.

Please find below my comments regarding the draft of the Final Report for the Denver study:

- 1. The process that was utilized in conducting the research was very well documented; however, could anything be done to make the appearance of the text more readable? For example, could headings be in bold type? Could more be done to differentiate the various topics?
- 2. In terms of the public meeting, I believe more should be added to page 19 regarding the lack of interviewees who attended. You will recall that the interviewers wanted to have each of the interviewees called by one of the interviewers a week or so before the meeting. The AIRRTC administration made the decision that it would be a breach of confidentiality to give the names and phone numbers of the interviewees to the interviewer who volunteered to make the calls. I think it is important to note that, in this instance, a recommendation of the interviewers was not followed, and you did not have the participation you would have liked from the interviewees.
- 3. I would like to suggest that when this study is replicated, you also assess the willingness of community leaders to activate the recommendations of the research--to take over where the research ends.

Finally, I would like to say in terms of the research process, that the close contact you kept with us, and your concern for the success of the project, was very important. . . .

--Sister Marie-Therese Archambault, O.S.F.



The report was great; the researchers did a wonderful job. The one problem I see for serving the Indian person with a disability is all the *red tape* that is involved in seeking benefits. This is always a problem for the Indian person with a disability; for example, getting transportation to places to fill out forms, and then finding that there is nobody or no program which can help them. Usually there is no referral to other services.

-- Marvis Blakesley

... Excellent summary of conduct of the project... Additional comments I have on consumer concerns are mainly concerning the nature of the problem issues. In most surveys of the general population, the main problems are usually almost all what you might call concrete or practical - or material - issues, such as housing, transportation, jobs, public access. But note that in this survey, this urban Indian population targeted nine problems out of forty issues, and the top six, as well as the eighth one, had to do with issues of communication and service delivery.

I took a look at the North Dakota-Western Minnesota survey where 84 Indians out of an N of 1574 responded to a statewide concerns report survey for the general population, and South Dakota where 164 Indians responded from an N of 2151. I have highlighted issues I saw as communication or social service delivery. You might compare the Indian responses to the general response. Of course, the two surveys are different from each other and from the Denver survey, since all consumer concerns surveys are developed by a consumer working group representative of the target population, which can also differ from survey to survey. I personally found the Indian and general responses to be similar, although in South Dakota the highest satisfaction rating given by Indian respondents was 70% compared to 75% of the general population. The similarity may not reflect the feelings of the typical Indian consumerno Indians participated in the working group in either state to develop the survey instrument. and almost all surveys were sent and returned by mail. That responses from Indians by white methods to a basically white survey were similar to white responses, while the Denver survey differed from the norm, may indicate the need for the consumer concerns report to be, as it was in Denver, developed and conducted by Indians, for Indians, in ways consistent with Indian culture, to identify issues truly meaningful to an Indian population.

The project evaluation comments by interviewers is a relevant and interesting addition to the appendices.

I would recommend that a shorter, slicker, less academic version of a final report be developed for use by the Denver Indian Center to present issues of concern to decision makers and service providers, include in fund raising efforts and grant applications, and use as a community organizing tool. I would suggest involving Wallace in this effort and I would be glad to help by providing other final report *good examples* from other surveys and commenting on drafts. . . .

--Barbara Bradford

The survey was all right. . . . Everything was covered in the interview--I felt good with my interviewer. I felt understood by the interviewer. I do not think there is much Indian community involvement towards meeting the needs of Indian people with disabilities right now. It was a good !dea to do this study and make an effort to get community involvement, I can't think of anything specific that needs to be done--nothing that I need. . . .

--W. C.

Being a disabled Native American (visually impaired) I thank you and others for all the considerations for attempting to try to change things. Now I know there are support groups that we can turn to. Thank you again.

-- Cecil R. Campbell



Following are my observations and commentary with reference to the draft of your final report of the needs assessment of American Indians with disabilities residing in the Denver Metropolitan Area (DMA).

Use of the Concerns Report Method of developing and conducting needs assessments was highly successful in obtaining useful information as well as gaining involvement of many Indian and non-Indian people in the survey. As researchers, I know you must meet deadlines and be timely in each phase of any given research. However, you and your colleagues exhibited much patience in utilizing this method.

You exhibited respect for the Indian people of this community and helped us to realize that there are unfilled needs of Indians with disabilities living in the DMA. Your recruitment, training, and retention of Indian people as interviewers contributed not only to the success of the needs assessment, but you also engaged in community development of the DMA Indian community. Providing opportunities to Indian individuals to participate in important activities affecting them leads to their growth in developing their capacities and it also contributes to the development of community leadership.

Conducting community meetings at which food was served was a concrete way of demonstrating respect for Indian people of Denver and demonstrated the trust you had in us to contribute in various ways to the planning and conduct of the study. We have been approached by two other organizations to gain our support for research they want to conduct among the Indian population of Denver, but they propose to conduct their research in a more traditional way. The investigators involved in these studies propose to plan and conduct them and not involve any Indians in any way except as respondents. I have suggested that they contact you to obtain your views on how to go about conducting research in an Indian community.

You handled the training, supervision, and support of the interviewers very effectively. I agree with the suggestion made by them that compensation should be made for the work they do in trying to track down interviewees, regardless of whether or not the interview was achieved. The on-the-scene supervisor could effectively determine whether the interviewer truly made the effort to contact an interviewee.

It was well that you did not cut back on the information you were seeking even though the interviews were lengthy, it took a lot of energy to sit through them, and in some cases produced some very emotional reactions. Even though the findings are applicable only to this population, the results provide a beginning for seeking further information, and upon which to design effective services and to improve existing services.

Although you tried to engage more Indians with disabilities to attend the public meetings, it was useful to encourage service providers to participate. I believe their new awareness of the need to improve services and to seek out (outreach) Indians with disabilities to use their services was a plus for your project. This assists local Indian citizens and Indian service providers to maintain pressure on rehabilitation programs and agencies to improve access to their services.

With respect to the <u>Recommendations</u>. I totally agree with the first recommendation. Service providers tend to provide sketchy information about available services and do not make certain the client understands the information. Secondly, this must be followed with proper and full referral services, including follow-up contacts to make certain the client has satisfactorily received needed services.

What is frequently overlooked is that outreach services involves more than provision of information. It includes, but is not limited to, listening carefully to the person in need, asking questions, previding emotional support as needed, providing practical suggestions, and helping the person overcome barriers to service. The entire process should lead to a mutually trustful working partnership between the provider and client so that the client is served adequately with respect and dignity.



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I also concur with and hope to promote the fulfillment of the other seven recommendations arising out of this study. I believe Recommendation No. 3 should be taken seriously. If a large portion of this respondent group is aging, it is necessary to begin planning development of services and designing effective means to truly create hassle-free access to services for the older client with disabilities. Issues around favoring one generation over the other should be dealt with in such a way that all Indian people with disabilities receive maximum available services.

As always, it is very important to constantly recruit, hire, train, and retain Indian people to become service providers, planners, administrators, and the like. It is clear from this study, as well as other studies, that Indian clients are more comfortable with and relate more positively to Indian providers of service.

I concur with all four areas identified as needing further study, especially the need to obtain information on the younger Indian population with respect to needed rehabilitation services. All programs at the Denver Indian Center encounter young people with varying degrees and types of disabilities. Basic to this is that many of them do not even get periodic medical examinations.

Finally, this study provides a foundation to systematize on joing information gathering and to engage in more effective planning, administration, and evaluation of ongoing community education on disabilities and services available to deal with them.

Thank you for the opportunity to comment on the study. Although I am no longer employed by the Denver Indian Center, I continue as member of the Indian community, vitally interested in this matter.

--John H. Compton

Thanks very much for keeping me informed about the recent disability research project in Denver and for allowing me to review the draft report. . . .

The report seems very thorough, sensitive, and informative. In terms of the research objectives and methodological limitations, the outcome seems quite sound and the results should be very useful for planners and service providers. What will come of the recommendations is hard to predict, but the fact that the Indian community contributed significantly to this research should prove beneficial in several ways.

Organizationally, my only criticism/suggestion relates to the lack of an introductory overview or executive summary. It would be helpful to have one since it takes a while to get a sense of the purpose and general outcome of the study, and a brief summary up front would more effectively keep the reader's attention, and hook his/her interest.

In terms of presentation of results, my only reservation is that those of us whose research and service provision interests focus on the elderly (by federal program definition: 55 and older) cannot readily use the results section (including the figures) to compare your findings with those of numerous other studies in which data on activities of daily living, disabling conditions, and self-reported health status are broken down by age categories. Agencies which serve the elderly would need those breakdowns in any proposals asking for increased funding for aging services for Indian and other ethnic elderly.

Overall, I am impressed with the study and the way it was conducted. It has inspired me to think about reworking and updating some of my earlier work related to disabilities and culture change among American Indians and Alaska Eskimos. . . .

--Lynn Mason



One of my concerns was that the selection of participants may not have been all that scientific . . . It seemed that a number of persons participating were identified by a chain of word-of-mouth referrals, and that such a network is not necessarily representative. In fact, people with disabilities often are averse to participating in this sort of activity, and yet they may be the ones with the greatest need.

In my own case, I have no critical need for social or medical services—although if circumstances changed, then transportation and medical services would become a real problem. Even now, however, transportation is somewhat of a problem. For example, right now I cannot get to the bus stop because I cannot walk such a considerable distance, but I do not quality for transportation assistance because my household income level is too high. I feel that I am between a rock and a hard place, and as a result, I am slipping through the cracks. If I maintain an adequate income level to be self-sufficient, I no longer qualify for benefits, but my income level, after taxes, medical treatment, insurance, and living expenses, does not allow for the additional expense of special transportation. So I do not have access to the bus.

Overall, I was well-pleased with the interview, especially with the interviewer's part in eliciting additional information from me, the respondent. For instance, I was asked about my practice of the Indian Medicine Way. I had not really thought about it, or considered that I did use this method, but as I talked I discovered that I have practiced the Indian Way in the past and do so at present. I have found this psycho-spiritual treatment to be very potent, and consider it one of the most effective treatments I have received for my multiple sclerosis. I do not understand how it works, maybe that is not necessary or ever desirable to know, but I do know that it works and I have somehow improved because of it. It is a rite that needs to be renewed at least once a year, however, and it requires travel to Oklahoma. From Denver, the nearest Longhouse is 900 miles away, and there is no provision made through services for Indian people with disabilities for transportation to a location where Indian Medicine is available. I would like my insurance to provide access to Indian Medicine, but I doubt that is going to happen.

-- D. Brant Montour

I am very pleased to see American Indian rehabilitation research conducted here in Denver. It will inform both Indian and non-Indian on existing problems that working together can improve the findings outlined in your research.

More than 50% of American Indians live in urban areas according to current estimates, but urban health programs have never received proper funding for health delivery services and have diminished by 70% in the last ten years. Due to this, hundreds of people have had to seek out other means of getting help.

Hundreds of American Indians have no role number and cannot provide documents of verification so accountability is lost. If all could have been included in your research, the results would be overwhelming . . .

I would like to make the following recommendations which if could be considered, would eliminate many of the problems that it seems most American Indians have and are prominent here in Denver.

There are a lot of individuals who want to apply for Social Security benefits, rehabilitation, or other assistance, but do not know how to apply. Everyone must learn to take personal responsibility to keep records of employment and earnings, receipts, etc. Social workers cannot do this. They are vital to receive assistance, but more vital if information is lost in the process of paperwork.

There is an area here which concerns me. A lot of individuals are rejected without reason so therefore lose rehabilitation or other assistance. Social Security employment records are very, very necessary and must be kept up to date. Sometimes reports do not match; errors are made in reports that are on file, jobs are not accounted for and deleted; computer errors are



made--all of which can and do disqualify people who have rightfully earned their credits. In order to investigate the denials, retrieve records and make these corrections, a person needs to be trained for that position as it is technical. One paper error can ruin a person's life and it happens often. There are over 8,000 laws which are passed out of Congress every year, many which apply to those issues. One may think they are entitled to benefits, but lost something a year or two ago. I recommend this position being made at the Denver Indian Center.

Most rehabilitation programs include psychotherapy. Physical rehabilitation is necessary after many accidents, surgeries, etc., but in order to get the full treatment, many American Indians feel they are compelled to comply and object.

The terminology for rehabilitation is to restore to a former state or back to the way a person was. Psychological treatment is based on what was evaluated as normal function of one's behavior, but was not evaluated in regard to Earth Behavior or Culture.

To all Indians, Mother Earth is the divine source of mortal and spiritual life and all living things become their relations. Indians become then, a geographic race of people by nature and natural phenomena. That is the foundation of all Indian people. When all living things and Mother Earth is hurt or destroyed, so is, the Indian and he/she will respond to that. Most of that person's recovery depends upon the Medicine Way or Spiritual Way taking them back to earth by the way they understand and were taught by their elders and medicine men. This is why Indian people ask for and want the traditional way of healing.

The Denver Indian community is blessed with spiritual people who serve in this capacity and assist often. To help larger groups of those in rehabilitation programs is rewarding, and I recommend that our Indian organizations dealing with mental health, rehabilitation and future planning find the means to incorporate more cultural methods of healing within the system.

Perhaps a bill could be introduced to the Senate Select Committee for Health Care Amendments for physical and mental practitioners allowing for the integrity of both psychical and religious practice for positive behavior modification. I think the results would be a real contribution to the progress of health care for American Indians.

I also recommend that medical practitioners come together with the American Indians to understand the cross-culture methods of healing and progress of health care. If these needs could be met, many problems will disappear.

You are to be commended for a job so well done in Denver, and I hope through your many efforts the research will support the needs of so many American Indians who need rehabilitation assistance. My appreciation and thank you!

--Indian Rolling Waters

I thought that the final report was good, and the conclusions were right, but it was too long! By the time I got to the end, I had forgotten what I had read--it was really too much. I also thought the <u>Consumer Interview</u> was too long as it sometimes took two to three hours to go through with the interviewee. This can be hard on people, especially people with a handicap such as a hearing loss, or a physical disability which makes staying in one place for a long time difficult and uncomfortable. About one hour for an interview is long enough, and then the interview should all be done in one session--after the first session, the interviewee is often no longer interested.

--M. T.

The mission of the Colorado Rehabilitation Services is to assist individuals who are physically and/or mentally handicapped attain a level of functioning that will enable them to enter, re-enter, or maintain employment and enhance skills necessary for living



independently. The community-based needs assessment research, being conducted through Northern Arizona University (NAU), suggests that Colorado Rehabilitation Services has room for significant improvement of our efforts to fulfill our mission where the Native American population of Denver is concerned.

As a result of the research, we are making a concerted effort to impart knowledge of the availability of Rehabilitation Services to Indian people with disabilities. I have met with administrative staff from the Denver Indian Center and Denver Indian Health and Family Services to lay groundwork for making our services accessible to Indian people living in the Denver area. Rehabilitation counselors have been assigned to both of the above facilities. Since our agency has the same problem locating Americans Indians with disabilities as NAU did for the research project, we are hoping to improve the process through our enhanced outreach efforts. I am concerned that the Indian youth (14-22) were not found; consequently, neither the youth nor their families were interviewed. I intend to address this issue shortly after school starts this Fall through our youth program and school personnel. With approximately 20,000 Indian people living in the metro Denver area, it seems to me there are youth out there who might also need our services. The school systems present the most obvious means for locating them. If the Rehabilitation agency is to follow the advice of Lewis (cited in Red Horse, Tewis, Feit and Decker, 1978) and follow the sequential path by outreaching to people in their homes rather than through pamphlets at health care facilities, we must first learn about where they live. One of the reasons for us to network with Indian Health Services, the Indian Center, school system, etc. is to avoid duplicating effort.

During the public meeting on the evening of April 17, 1990, one young man commented that "you've got to hire Indian people to help Indian people." Colorado Rehabilitation Services is on record with its recruiting efforts for employing Indian people. The fact is that we have not been successful in finding qualified American Indian rehabilitation counselors. We fully intend to continue our search for appropriate staff. I believe we need to arouse interest in the field early in a student's high school or even junior high school years, if we are going to be successful in developing and maintaining professional staff resources.

There is sometimes a problem of economics and other available resources when it comes to addressing needs identified through research. There are many activities we would like to provide; but often we don't have adequate resources to do so. I recommend that one of the federal agencies offer an opportunity through the grant's mechanism, similar to the Section 130 or migrant projects, for establishing an American Indian Urban Rehabilitation outreach program. Our agency has a difficult time locating this population.

Thanks for the opportunity you have given me throughout this whole project. I look forward to your final product. Please contact me if I can be of further assistance.

--James Weiland, Coordinator for Native American Programs, Rehabilitation Services, State of Colorado



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Please find	l below r	ny comments regarding the <u>Final Report</u> . I ask that you:
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